Aging and wellbeing

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Aging and wellbeing

Investigating elderly preferences and values

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Chapter 1

General introduction and outline of the thesis

1.1 Elderly healthcare spending, chronic disease and quality of life.

Aging is a progressive process of deterioration, comprising physical and mental domains. It constitutes loss of ability to maintain and function at previous levels of achievement. Moreover, aging is a personal process which includes both positive and negative experiences. [1] Health related quality of life (HRQoL) is one popular outcome measure to assess the effects of aging on what people judge to be important in their lives. In the aging process, personal value systems, culture and health status play an important role in determining what people view as acceptable quality of life (QoL). [2, 3]

For the elderly population it might be of special importance to receive a more holistic multidisciplinary treatment, which does not focus on specific symptoms and physical aspects, but rather pays attention to social and psychological effects of aging. Adapting clinical guidelines to take into account multi-morbidity is essential, with a balance being maintained between benefit, harm and individual preference. [4, 5]

The deterioration or senescence mentioned above at one point is considered chronic disease, which subsequently results in increased use of health care resources. [6] In addition, multi-morbidity is of specific concern for the elderly population, and current health care and public policy should make special

provisions for the population suffering from more than one chronic condition. [7, 8] A study conducted in the Netherlands indicated that 30% of individuals aged 65-74 years suffered from four or more chronic conditions, while this figure was 55% percent for individuals 75 and over. [7, 9] Identifying the amendable risks factors behind the multi-morbid dynamic is essential [10]. Evidence shows that health care utilization is not only related to type and number of chronic conditions, but also to socio-economic factors such as income and age. [10, 11] Essentially, this would indicate gathering current clinical data, eliciting expert opinions and population preferences to produce interventions and guidelines specifically for the multi-morbid population. [4, 12] Developing a system for cross-referencing multi-morbid clinical guidelines is not a simple task, but current strategies are clearly insufficient in delivering health care to those that need it most. [4] Ideally, clinicians should have access to an evidence system which recommends initiating, avoiding or halting treatment of multi-morbid conditions. [4] Ultimately, the application of the multi-morbid guidelines should translate into better patient QoL, and more appropriate and thus cost-effective healthcare spending. [13]

European countries like France, Germany and the Netherlands are spending one in eight euros (of gross domestic product (GDP) on healthcare. Other countries like Canada, the UK and the US also spend large portions of its (GDP) on healthcare. [13] Projections for the next 50-years all predict further increases in spending on healthcare. The question remains whether spending

more and more on healthcare services is producing the appropriate value (benefit) for money, [13] while still positively affecting elderly QoL.

1.2 Measuring health

1.2.1. Current perspective

Commonly QoI is measured by using a preference based instrument like the EuroQol-5D (EQ-5D), the Health Utility Index (HUI) or the Short Form Health Survey (SF-6D) also for the elderly. [14, 15] Preference based instruments have certain limitations and advantages when used for economic evaluation. [16] The most prevalent criticism is that preference based instruments are not sufficiently sensitive to distinguish between population health states. Also, a single index score may be misleading and even scoring by dimensions may be too generic since the specific (social) circumstances of the individual cannot be taken into account. [14, 16] However, the preference-based method is still widely used to measure health states all over the world.

It remains critically important to distinguish between measuring and valuing health. Measuring health involves numerically describing health according to different domains like ability to walk, remember information and perform usual activities. Valuing health involves the relative value a person will place on the change, whether positive or negative, on the dimensions or the

health states. [16] Different techniques exist for valuing health states: they include Time Trade Off (TTO), Standard Gamble (SG), Visual Analogue Scale (VAS), magnitude estimation (ME), person trade off (PTO) and discrete choice experiments (DCE). [10, 16, 17] The goal of the research and the population undertaking the valuation exercise will to a large extent determine the technique which can be applied in valuation of health states. [16] It is of specific importance to consider the elderly population in measurement and valuation exercises, to minimize the cognitive burden placed on them. [18]

1.2.2. Measuring and valuing elderly health care.

To effectively measure and value elderly health care the shortcomings of current interventions should be investigated. In his thesis entitled, Promoting wellbeing in frail elderly people, Schuurmans mentions shortcomings of current interventions: 1) Although current interventions may work, it often remains unclear how they work due to a lack of a clear evidence based methodology and outcomes; 2) existing intervention focus mainly on health related quality of life(HRQOL) ; 3) present day interventions focus on providing care and coping strategies, while elderly interventions should proactively focus on prevention and adaptation to achieve superior Qol; 4) current intervention do not address intricate multi-morbid conditions. [19]

Considering these specific shortcomings in elderly interventions, together with the general requirements for effective measurement and evaluation of health a new approach is warranted. A new approach should be grounded in theoretical evidence and concepts. It should include broader conceptions of Qol, and focus on proactively promoting and acquiring skills to ensure effective self-management while aging. Finally, it needs to address the complicated issue of multi-morbidity that affects a large portion of the elderly population. A seemingly appropriate theory developed by Sen and Nussbaum, called the capability approach has been proposed. [20]

1.3 An alternative approach

1.3.1 The capability approach

The capability approach is a broad philosophical concept, which was first introduced by Amartya Sen and subsequently developed further by others like Martha Nussbaum. [21] The main framework of the capability approach revolves around capabilities, resources and functionings. [22, 23] Capabilities can be described as the possibilities, i.e., what people think they can do, while functionings are what they actually achieve with the available resources. [22, 23] It has been proposed that the capability approach might be applied to individual medical decision making as well as to macro level resource allocation decisions. [24, 25] The capability approach relates to individual autonomy and the opportunities a person has,

while also relating to the concept of QALY's. [24] Although the link between capabilities and QALY is not straightforward, re-interpretation of the QALY to include health and non-health functionings may resolve many of the shortcomings of the traditional QALY method. [25]

Crucially, for the capability approach to be effective it should be applied on different levels of operationalization. [26] The first of which would be on the conceptual level, which identifies the important functionings that determine human prosperity and well-being. The second level is the policy level, which denotes policies and guidelines. The third is on intervention level, which details actions in specific medical cases, interventions and health services. However, a coherent procedure which is transparent, evidence based and precise will require medical guidelines, with input from patients or civilians. [26] A clear course of action can then be taken, either at the point of health care delivery or on policy level. Ultimately, the ideal would be to construe a package for universal health benefit with health capabilities at its core, which would include health-care, health related social and public health services.

Addressing the issues of health maximization and resource allocation is a complex combination of ethical, social and economic factors. For this reason, the capability approach may be well suited for this purpose, as it incorporates ethical systems into

personal preference which gives rise to a multivariate approach to 'health". Whether it is measuring and valuing non specified capabilities or whether it is measuring and valuing a "capability set"(set of functionings which is achievable), the process should include: 1) non-health related dimensions; 2) the measurement and valuation should be performed by the patients; 3) the valuation technique should be appropriate for the patients performing the valuation exercise; 4) finally the patients themselves will determine the benefit of the achieved capability or functionings. [22, 26, 27]

1.4 This Thesis

1.4 .1 Aim

Aim of this study is to investigate elderly Dutch disability, quality of life and health valuations and the influence of chronic disease and multi-morbidity.

Research questions

* How will chronic disease and *multi-morbidity* influence elderly disability projections?
* How do a sample of Dutch and South African elderly score and value health states from a utility instrument *(HRQOL)* like the EQ-

5D+C compared to a capability instrument *(functionings)* like the Currently achieved functionings (CAF) ?

* How do the elderly value hypothetical health states in terms of a utility instrument *(HRQOL)* like the EQ-5D+C compared to a capability instrument *(functionings)* like the CAF.

* How do the elderly rate/score their *own health* using utility and functionings in light of the questionnaires utilized

1.5 Possible implications

High prevalent disease and multi-morbidity will affect both male and female elderly, but particularly non-fatal disease should be addressed since it has a pronounced effect on time elderly spend in a disabled health state.

* The utility and capability questionnaires factually describe two different concepts, which will provide a better understanding of the interaction between HRQoL and wellbeing.

* Value judgements by the elderly, of utility and capability health states, will provide implicit suggestions on health states deemed to be acceptable and unacceptable. Empowering the elderly to achieve acceptable health states might be of critical importance.

* Application of personal resources to achieve QoL and wellbeing outcomes is a highly individualized process. By allowing elderly to adapt to disease affected health states and focus on utility and capability that are achievable, profile specific QoL and wellbeing goals are obtainable.

1.6 Outline of the dissertation

The first part of the thesis, i.e. **Chapter 1** introduces the core research problems and objectives. **Chapter 2** deals with the description of old age quality of life, life expectancy, disease profiles and the role of multi-morbidity and elderly preferences in determining elderly health care utilization. **Chapter 3** describes the multistate life table approach used to investigate elderly potential disability in the presence of chronic disease and multi-morbidity. **Chapter 4** describes the pilot studies performed to test the feasibility of using the EQ-5D+C and CAF questionnaires in elderly QoL research. **Chapter 5** reports on the valuations, performed by the elderly, of the utility and capability health states.**Chapter 6** reports on the use of the EQ-5D+C and CAF questionnaires, to describe and determine the spectrum of elderly QoL.

The final chapter**, Chapter 7**, summarizes the main results and reviews the overall conclusions of the health state descriptions and valuations, disability projections and the implicit judgements on acceptable and unacceptable health states. In addition, we describe the practical implications of the research results for elderly health care and the contribution of the project to the current body of knowledge. Lastly, we make recommendations for future research.

Chapter 2

Review of literature: Relations between aging, health care costs and wellbeing.

Introduction

When referring to elderly, what is usually implied is a certain calendar age beyond which individuals are considered 'elderly'. Frequently people aged 65 and older are implied, without directly indicating a certain demeaning qualification regarding (mental) health or otherwise. As such, however, ageing comes with declining physical and mental reserves, ultimately deteriorating and failing. [1] More generically well-being and quality of life (QoL) are the outcomes that are most relevant, and for the elderly in particular. QoL may be decomposed into factors like levels of perceived control, self-management of aging and cognitive functioning. [2, 3]

Intriguingly, very little information is available demonstrating the health care choices of healthy elderly people and those of frail elderly. [4] It may be that although they are part of the same age group, the healthy elderly person will have different health care preferences compared to frail elderly [5]. Socio-economic factors like education, social status and which setting the elderly reside in are independent factors that also relegate the elderly into specific subgroups regarding health and care preferences. [6, 7] These preferences might not be the same for all the subgroups of elderly and should not be overlooked when developing treatment and care alternatives for future elderly populations.[8]

However, it is as yet unclear what value and weight the elderly place on the factors that determine their quality of life (QoL).[9]

Importantly, aging populations have recently led to considerable debate about the implications for sustainability of health care services. [10, 11] As in other sectors, health care services for the elderly should be cost-effective, i.e., maximizing the (health) care benefits among the elderly at acceptable costs. [10]

However, recent studies suggests that hypothetical elimination of disease will not necessarily have the same effect on longevity and health care spending. Eliminating a disease with a pronounced effect on longevity might increase health care costs over the life time of the individual patient. [12] Thinking along these lines, one also recognizes the fact that at some point choices will have to be made as to what services will and will not become part of the (publicly) covered package.

In absence of a comprehensive notion of age and phase of life appropriate outcomes of health care, we, as a general aim, set out to review the literature on elderly quality of life as determined by aging and the consequences of prevalent elderly disease.

Search strategy

A literature search was conducted to answer specific research questions. The research questions were: What are the effects of prevalent disease on elderly quality of life and, 'Which factors are the most important predictors of Elderly Capabilities/Quality of life'

and ‘What are Elderly quality of life and wellbeing preferences and how should these influence future treatment options.

There were no restrictions with regard to the origin of the studies, however, they had to be written in English, and published between January 1995 and December 2018.

The inclusion criteria was simplified by only selecting articles which included the three major concepts of the study:

1) Elderly disease AND morbidity.

2) Elderly capability AND quality of life.

3) Elderly health care preferences AND health care costs.

Notably, case studies, articles with ambiguous results and articles with a purely qualitative approach were excluded. A computer-assisted search via Pubmed from 1 January 1995 to December 2018 was performed. From the articles found the reference lists were hand searched to identify other possibly relevant articles.

Results and Discussion

Aging, morbidity and wellbeing

From the literature it is clear that the vast majority of people aged 65 and over has either one or several chronic diseases. [13] Prevalent disease, multi-morbidity, demographic characteristics and non-health variables like patient age, level of education and living arrangements segment the elderly population into specific subgroups with distinctive morbidity and mortality profiles. [6, 14, 15] Moreover, community-based surveys have recorded mortality rates up to 30-40% within one year after diagnosis and 60-70% within five years after diagnosis. Likewise, looking at the demographic assessment that was performed on the data from the Longitudinal Aging Study Amsterdam (LASA) it becomes clear that the mortality rates for COPD, cancer and cardiovascular disease are highest. [16] It is however important to remember that morbidity and disability caused by disease can cause significant long term suffering for elderly patients, while survivors of critical illness have considerable ongoing health care needs. A reasonable body of evidence suggests that the costs associated with survivorship is extensive. [17] Intuitively diseases classified as non-fatal will cause elderly men and women to spend more time in a diseased state and thus requiring long-term health care. Indeed elimination of highly fatal diseases, such as 'neoplasms', would results in a decrease in ''hospital care'' costs, and a considerable increase in ''nursing and residential care facilities'' required. [18] Reducing fatal outcomes of one disease would still allow morbidity from other chronic conditions to emerge. The latter may ultimately necessitate formal and informal care. [19] It is

therefore important for future interventions to focus on reducing morbidity and risk factors rather than focussing on mortality prevention.

Primary prevention could increase function in middle-aged and older adults in whom some degree of physiological dysfunction has already occurred. The overarching objective would be postponing or possibly averting the transition to functional limitations or medical disability. In contrast, secondary prevention strategies should advance or preserve function in middle-aged/older adults with already overt dysfunction. [20] An additional and important advantage would be that prevention would contribute to a sustainable health care system. Evidence indeed reveals that individuals suffering from multi-morbidity have more face to face and telephone consultations with a general practitioner, more minor surgeries, increased use of prescription medication, more home visits and more referrals to specialized care. [21]

Importantly, wellbeing arises from a complex interaction of health and non-health dynamics such as social interaction, pleasurable activities and having a purpose in life [22] Experiencing sufficient abilities in health domains, such as mobility, cognition and. vision, generally has an effect on non-health aspects, which clearly are important for successful aging as well. [23] To determine elderly health related quality of life (HRQoL) and wellbeing, it is recommended to use a generic preference based instrument, like

the EQ-5D in conjunction with the ICECAP-O or the ASCOT. This will enable the measurement and valuation of broader quality of life benefits as defined by the elderly. [24]

The EQ-5D is a well know preference based instrument used to describe and value health care and mainly focusses on the attributes concerned with HRQoL. [25] The ICECAP-O is however an instrument that relates to the concept of the capability approach and includes attributes like attachment to friends and family, having a purpose in life and experiencing a sense of control over one's life. [26] The capability approach advocates the idea that capabilities (opportunity to achieve) and not necessarily functioning (actual achievements) determine people's wellbeing. [27] Reduced health may limit older people from engaging in activities, but reduced health does not necessarily affect overall well-being. Even in the framework of chronic conditions and reduced mental and physical health, better capabilities can lead to superior well-being. [28] It is clear that health economists, physicians, care givers, the elderly and the general public may have very different views on the merits, and thus on the cost-effectiveness of current health care for the elderly. Indeed an important and timely area for research is recognized. Also, since we lack actual preferences of the elderly for various health states, which thus far have not been revealed, these too should be studied and subsequently reflected in policy decisions. [29] The fact that older individuals are more concerned about how they function than what amount of recovery of physical or mental reserves they

are able to attain reflects the notion that actions are readily transformed into functional reality for people in advanced age. [30] At present healthcare professionals, provide medical care targeting restoration of organ function. In contrast, surveys among the elderly often confirm that they want to restore independent daily activity, rather than to attain a restoration of organ function. [31]

Patient centred health care for the elderly population

A call for reform in the Dutch health care system is apparent, i.e. a person-centred operationalisation of the new dynamic concept of health is foreseen. [32] The purpose of treatment should be in line with the patient's own needs. Ignoring the needs of the elderly could indirectly lead to discrimination against the elderly in terms of health advancement and disease prevention and, hence, an age based allocation of public health care. [33] Finding a solution for this problem is important, since it is clear that the elderly population will increase substantially over the next three decades, thus indicating high health care related costs for the ailing elderly population. [34, 35]

Possible cost-effective interventions can be the incorporation a physical activity intervention as a primary prevention strategy which may conserve: mobility and muscle strength by curtailing motor unit loss/improving muscle activation strategies or preserving muscle mass; vascular function might be preserved by

conserving nitric oxide bioavailability; diastolic heart function might be maintained by preventing age-related cardiac fibrosis [20]. Additionally, evidence supports the use of concomitant exercise for improving a range of health-related factors and is effective for increasing gait speed, lower limb strength, and decreasing trunk fat in older adults. [36] Through health examination for older adults those who are at high risk of limitations in functional capacity, may be identified. These high-risk individuals can be offered interventional programs (fall prevention, undernutrition prevention, cognitive decline prevention and physical exercise) to promote various physical and mental functions necessary for older people to preserve independence in their daily life. [19] Finally, routinely screening older adults at risk for mobility limitation and addressing functional inadequacies and environmental obstacles with exercise and mobility devices, and effectively managing pain in the elderly may lead to enhanced function and wellbeing. [37, 38]

Therefore, the subjective perceptions that individuals have about themselves, and the subjective perspective through which individuals describe the principles to evaluate their HRQoL and wellbeing are fundamental for empowering the process of engagement and should be included in real-life health engagement scenarios. [39] Equity for all in need will secure the best result for society and for current and future generations. Health is a commodity like nothing else. Preserving, maintaining and investing in it should be cultivated from early in the life course of the elderly. The benefits of shifting the minds of only a small

percentage of individuals from a passive needs driven health perspective to an active and engaged participant can have enormous financial and wellbeing implications for society.

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Chapter 3

Relative contribution of various chronic diseases and multi-morbidity to potential disability among Dutch elderly.

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Abstract

Background: The amount of time spent living with disease greatly influences elderly people's wellbeing, disability and healthcare costs, but differs by disease, age and sex. **Methods:** We assessed how various single and combined diseases differentially affect life years spent living with disease in Dutch elderly men and women (65+) over their remaining life course. Multistate life table calculations were applied to age and sex-specific disease prevalence, incidence and death rates for the Netherlands in 2007. We distinguished congestive heart failure, coronary heart disease (CHD), breast and prostate cancer, colon cancer, lung cancer, diabetes, COPD, stroke, dementia and osteoarthritis. **Results:** Across ages 65, 70, 75, 80 and 85, CHD caused the most time spent living with disease for Dutch men (from 7.6 years at age 65 to 3.7 years at age 85) and osteoarthritis for Dutch women (from 11.7 years at age 65 to 4.8 years at age 85). Of the various co-occurrences of disease, the combination of diabetes and osteoarthritis led to the most time spent living with disease, for both men (from 11.2 years at age 65 to 4.9 -years at age 85) and women (from 14.2 years at age 65 to 6.0 years at age 85).
Conclusions: Specific single and multi-morbid diseases affect men and women differently at different phases in the life course in terms of the time spent living with disease, and consequently, their potential disability. Timely sex and age-specific interventions targeting prevention of the single and combined diseases

identified could reduce healthcare costs and increase wellbeing in elderly people.

Introduction

The ultimate aim of healthcare should be to reduce disability and increase wellbeing. [1] Both disability and wellbeing are broad concepts, however. Because disability is usually defined as a limitation in physical or mental functioning, caused by the presence of disease, [2] the amount of time spent with disease is an important factor to consider when determining both disability and wellbeing. The more time spent living with disease, the higher the level of potential disability experienced, and the higher the individual and healthcare related costs.

Reducing disability and the associated healthcare-related costs becomes even more challenging with the rapid ageing of populations in Western societies, particularly in Europe. Demographic projections indicate that 30% of the European population will be aged 65 or over by 2050 .[3] It is however clear that not all public health interventions aimed at addressing morbidity and longevity are effective. [4] Understanding which group of elderly people should be targeted by disability/disease prevention programmes is important for reducing the burden of highly-prevalent diseases and combating multi-morbidity among the elderly. [5] Timely interventions targeted at vulnerable groups

may be able to alter undesirable health pathways and postpone disease development. [6] This warrants a closer look into differences by disease, age and sex in time spent living with disease and time spent living with comorbidity.

Many people aged 65 and older suffer from chronic multi-morbid conditions associated with increased disability and reduced health-related quality of life (HRQOL). [7] Suffering from multi-morbidity also causes elderly people to use healthcare resources more often and to require more frequent hospitalization than when suffering from a single disease .[8]

Multi-morbidity and type of single chronic disease influence to a large extent the time spent living with disease. [9, 10] Diseases like COPD, cardiovascular disease (CVD), dementia, diabetes and osteoarthritis are all diseases which have a considerable impact on elderly people's disability and associated quality of life and frequently occur together. [11] Future projections indicate that high-income countries can expect ischemic heart disease to account for 5.9 percent of the total disability-adjusted life years by 2030. Other cardiovascular diseases and COPD will account for 4.5 percent and 2.5 percent of the total disability-adjusted life years in 2030 respectively. [12]

Alongside chronic disease profiles including multi-morbidity, age and gender also play an important role in determining health transitions and the time spent living with disability in elderly people. [13-17] Health transition typically refers to transition from a

healthy state to a diseased or disabled health state. It has been noted that fewer elderly women are in good health than men, yet women live longer than men. [13] Women are also more likely to suffer from multi-morbidity compared to men. [13] The experience of disease and disability from the perspective of 'young' elderly people might also be very different from older and very old elderly people. Therefore, age and sex adjusted outcomes are needed to effectively plan for healthcare services for the aging population. [18]

Understanding the effect of different chronic diseases and their co-occurrence on morbidity across the elderly life course is essential to improve the provision of cost-effective treatment options and taking into consideration the variable effect of chronic disease on health transitions in the male and female populations at different older ages. [18-20]

This study aims to assess how various single and multi-morbid conditions will influence life years spent living with disease for elderly in the Netherlands, thereby emphasizing differences between men and women and differences by age over the remaining life course.

Methods

Setting and data sources

Box 1 lists the specific diseases and disease combinations we included in our study.

Congestive heart failure (CHF)	CHF+CHD
Coronary heart disease CHD)	Dementia+stroke
Breast cancer (women only)	Diabetes+osteoarthritis
Prostate cancer (men only)	CHF+osteoarthritis
Colon cancer	CHF+CHD+diabetes
Lung cancer	Dementia+stroke+CHF
Diabetes	Dementia+stroke+lung cancer
Chronic obstructive pulmonary disease (COPD)	Dementia+stroke+colon Cancer
Stroke	Dementia+stroke+prostate cancer
Dementia	Diabetes+osteoarthritis+dementia
Osteoarthritis	CHF+osteoarthritis+COPD

We assessed the average remaining number of life years that are expected to be spent living with various single and combinations of diseases for Dutch men and women aged 65, 70, 75, 80 and 85 in 2007. The specific diseases were chosen because they were the most prevalent within the Dutch elderly population. [21-24]

The disease combinations were included to demonstrate the effects of the combination of potentially fatal diseases (CVD, cancer and COPD) and the combination of mostly non-fatal diseases (osteoarthritis, dementia and diabetes). In doing so, a maximum of three diseases were combined.

We obtained the health data below on the total population in the Netherlands in 2007 by age (0-4, 5-9, …, 80-84, 85+) and sex. Population numbers and all-cause and cause-specific death numbers were obtained from Statistics Netherlands. Disease incidence rates and disease prevalence were obtained from the National Institute of Public Health and the Environment. [25] The data were freely available to the public and, according to Dutch legislation, no ethical approval was necessary to perform the research.

Multistate life tables calculations

We applied multistate life table calculations to each disease and each disease combination. Multistate life table calculations (often referred to as multistate life tables) are an important demographic tool used to estimate the expected average time spent in a given state from a particular age, in our example the time spent living with and without a particular disease (or disease combination). [26] Essentially, a multistate life table is an extension of the general life table in which the expected (remaining) number of years of life (life

expectancy) is assessed based on age-specific mortality rates. [27] Multistate life tables, however, compare more states than life and death, and more transitions than just dying/mortality, and use age-specific transition rates linked to the various transitions as input for the calculations. In our case, we considered three states: 1) without a particular disease or disease combination (non-diseased), 2) with a particular disease or disease combination (diseased), and 3) death. We then distinguished three transitions: 1) mortality from non-diseased to death, 2) mortality from diseased to death, and 3) diseased from non-diseased. We used the relevant age and sex-specific transition rates as input: 1) mortality rates in the non-diseased population calculated by dividing the all-cause death numbers by the non-diseased population, 2) mortality rates for the diseased population calculated by dividing the cause-specific death numbers by the diseased population, and 3) the disease-specific incidence rates. The diseased population was calculated by multiplying disease prevalence by the total population, and the non-diseased population was obtained by subtracting the diseased population from the total population.

Since the diseases considered are generally chronic, we assumed no recovery and thus excluded the transition from diseased to non-diseased.

We followed the life table calculations as described in detail by Nusselder and Peeters, [5, 28] which include the following steps: 1) putting the rates in a matrix format for each age, 2) transforming

the age-specific rate matrices to age-specific probability matrices, 3) using information from the age-specific probability matrices as input for the two life tables: one referring to the disease state and the other to the non-diseased state, and 4) applying the normal life table calculations to the two life tables to obtain the average remaining number of years spent living either with or without the disease.

Like previous studies, we assumed that transition rates were constant across the 5-year intervals. We applied the life table calculations to five-year age groups starting at age 0, and assumed that no one suffered from the studied diseases and disease combinations at birth. For the number of years spent living in the open ended age group for the various states we used life expectancy at age 85 in 2007 from Statistics Netherlands: 5.3 years for men and 6.6 years for women.

Multi-morbidity was estimated by combining single disease transition rates by simple addition, without interactions. [23, 29] For example, we estimated the multi-morbidity of CHD and CHF by adding (1) the CHD incidence rate to the CHF incidence rate, (2) the CHD diseased death rate to the CHF diseased death rate, and (3) the CHD non-diseased death rate to CHF non-diseased death rate. Using the combined transition rates as input for the multistate life table calculations, we obtained the average number of years Dutch men or women aged 65, 70, 75, 80, and 85 can expect to live with CHD and CHF combined.

Results

In 2007 Dutch men and women aged 65 could expect to live another 17.4 and 20.9 years on average, respectively. Of these remaining years, more years – compared to other diseases – will be spent living with either osteoarthritis (7.1 years for men, 11.7 years for women), diabetes (7.0 and 6.5 years, respectively) and CHD (7.6 and 5.0 years, respectively (Table 1). The same applies to Dutch people at older ages in 2007, although clear sex differences appear. Men can expect to spend the most years with CHD, starting from 7.6 years at age 65 to 3.7 years at age 85. Women can expect to spend the most remaining years with osteoarthritis, starting from 11.7 years at age 65 to 4.8 years at age 85. The share of remaining life time spent with disease increases significantly from one age group to the next for certain diseases, see Table 2.

Table1: Total remaining life expectancy and remaining life expectancy spent living with different single diseases (in years), for Dutch men and women aged 65, 70, 75, 80 and 85 in 2007

Remaining life expectancy spend with a certain disease[2]											
Age	Remaining life expectancy[1]	Diabetes	CHF	CHD	COPD	Osteoarthritis	Dementia	Lung Cancer	Colon Cancer	Prostate/Breast Cancer	Stroke
Men											
65	17.4	7.0	2.3	7.6	3.7	7.1	0.6	0.1	0.6	1.6	2.3
70	13.6	6.4	2.3	7.0	3.4	6.6	0.6	0.1	0.6	1.5	2.2
75	10.3	5.7	2.3	6.2	3.0	6.0	0.6	0.1	0.5	1.4	2.0
80	7.5	4.7	2.1	5.2	2.5	5.0	0.6	0.1	0.4	1.2	1.8
85	5.3	3.2	1.7	3.7	1.9	3.3	0.5	0.0	0.3	0.9	1.4
Women											
65	20.9	6.5	2.1	5.0	4.2	11.7	1.0	0.1	0.5	1.6	2.1
70	16.8	5.9	2.0	4.7	3.7	10.6	1.0	0.1	0.4	1.4	1.9
75	12.9	5.1	1.9	4.2	3.1	9.2	1.0	0.0	0.4	1.2	1.7
80	9.5	4.2	1.8	3.5	2.5	7.3	0.9	0.0	0.3	0.9	1.5
85	6.6	3.0	1.4	2.6	1.8	4.8	0.7	0.0	0.2	0.7	1.1

[1] The average number of remaining life years Dutch men or women in 2007 at the specified age can expect to live. [2] The average number of remaining life years Dutch men or women in 2007 at the specified age can expect to live with a certain disease

The share of remaining life time spent with diabetes, CHD and osteoarthritis increases significantly for men from one age group to the next, whereas this is only true for women with osteoarthritis. The share of remaining life time spent living with stroke, dementia, colon cancer, prostate/breast cancer and lung cancer does not change much over the life course for men and women.

Table 2: Share of remaining life years spent living with different single diseases (in percentages), for Dutch men and women aged 65, 70, 75, 80 and 85 in 2007

Age	Diabetes	CHF	CHD	COPD	Osteoarthritis	Dementia	Lung Cancer	Colon Cancer	Prostate Cancer	Stroke
Men										
65	40.2	13.3	43.4	17.8	40.7	3.5	0.8	3.4	9.2	13.2
70	47.0	17.0	51.3	20.3	48.6	4.7	0.9	4.1	11.3	16.0
75	55.0	21.9	60.5	22.7	57.9	6.3	0.9	4.9	13.5	19.6
80	62.8	27.8	69.7	24.9	66.8	8.5	0.8	5.7	15.9	24.2
85+	60.4	31.5	69.2	26.2	63.0	10.2	0.7	6.2	17.3	27.1
Women										
65	31.0	9.9	24.0	20.1	55.8	4.7	0.3	2.3	7.8	9.8
70	34.9	12.0	27.9	22.1	63.1	5.9	0.3	2.6	8.4	11.5
75	39.5	15.0	32.5	24.2	71.1	7.6	0.3	3.0	9.0	13.5
80	43.8	18.6	37.1	26.2	76.9	9.5	0.2	3.4	9.7	15.6
85+	45.2	21.4	39.8	27.4	73.1	11.1	0.2	3.6	10.3	17.3

When considering the combination of diseases, older Dutch men and women in 2007 could expect to live most of their remaining life years with the 'Diabetes + osteoarthritis' disease pair (Table 3). Dutch men aged 65 in 2017 can expect to live 11.2 years with diabetes and osteoarthritis combined, and Dutch women aged 65, 14.2 years. At age 85, the figures are 4.9 years for men and 6.0 years for women, respectively.

Table 3: Total remaining life expectancy and remaining life expectancy spent living with different combinations of diseases (in years), for Dutch men and women aged 65, 70, 75, 80 and 85 in 2007

	Remaining life expectancy[1]	Remaining life expectancy spend with a certain disease[2]										
Age		CHF+CHD	Dementia + stroke	Diabetes + Osteoarthritis	CHF+ Osteoarthritis	CHF+CHD+ Diabetes	Dementia + stroke + CHF	Dementia+ Stroke +lung cancer	Dementia +stroke +colon cancer	Dementia +stroke +Prostate /breast Cancer	Diabetes+ osteoarthritis + dementia	CHF + osteoarthritis + COPD
Men												
65	17.4	5.8	1.8	11.2	5.5	7.0	1.9	0.3	1.0	1.8	5.2	4.8
70	13.6	5.6	1.8	10.6	5.4	6.9	2.0	0.3	1.0	1.8	4.9	4.6
75	10.3	5.4	1.8	9.6	5.3	6.6	2.1	0.2	1.1	1.8	4.6	4.4
80	7.5	5.2	1.9	7.9	5.0	6.2	2.5	0.2	1.3	2.1	4.7	4.2
85	5.3	5.0	2.1	4.9	4.3	5.2	3.8	0.4	2.2	3.2	5.0	4.9
Women												
65	20.9	4.8	2.3	14.2	9.1	6.8	2.4	0.4	1.3	2.2	7.9	8.6
70	16.8	4.7	2.2	12.9	8.4	6.4	2.4	0.4	1.3	2.1	7.1	7.9
75	12.9	4.5	2.1	11.2	7.6	6.0	2.4	0.4	1.3	2.0	6.2	7.2
80	9.5	4.2	2.0	9.0	6.5	5.6	2.5	0.4	1.3	1.9	5.6	6.4
85	6.6	3.9	1.9	6.0	5.3	5.4	3.1	0.5	1.6	2.4	5.7	5.9

[1] The average number of remaining life years Dutch men or women in 2007 at the specified age can expect to live. [2] The average number of remaining life years Dutch men or women in 2007 at the specified age can expect to live with a certain disease

Again, important sex differences appear. Men can expect to spend more years with the ‘CHF + CHD’, ‘diabetes + osteoarthritis’ and ‘CHF + CHD + diabetes’ disease combinations, while women can expect to spend more years with ‘CHF + osteoarthritis’, ‘diabetes + osteoarthritis’ and ‘CHF + osteoarthritis + COPD’.

The proportion of remaining life years spent with disease also increases progressively from one age group to the next for the different combinations of diseases (Table 4). The exceptions are dementia and stroke and cancer combinations, where both men and women will spend a similar percentage of their remaining life years with disease from one age group to the next.

Table 4: Share of remaining life years spent living with different combinations of diseases (in percentages), for Dutch men and women aged 65, 70, 75, 80 and 85 in 2007

Age	CHF+CHD	Dementia + stroke	Diabetes + Osteoarthritis	CHF+ Osteoarthritis	CHF+CHD+ Diabetes	Dementia + stroke + CHF	Dementia+ Stroke +lung cancer	Dementia +stroke +colon cancer	Dementia +stroke +Prostate /breast Cancer	Diabetes+ osteoarthritis + dementia	CHF + osteoarthritis + COPD
Men											
65	33.3	10.3	64.4	31.6	40.2	10.9	1.7	5.7	10.3	29.9	27.6
70	41.2	13.2	77.9	39.7	50.7	14.7	2.2	7.4	13.2	36.0	33.8
75	52.4	17.5	93.2	51.5	64.1	20.4	1.9	10.7	17.5	44.7	42.7
80	69.3	25.3	105.3	66.7	82.7	33.3	2.7	17.3	28.0	62.7	56.0
85	94.3	39.6	92.5	81.1	98.1	71.7	7.5	41.5	60.4	94.3	92.5
Women											
65	23.0	11.0	67.9	43.5	32.5	11.5	1.9	6.2	10.5	37.8	41.1
70	28.0	13.1	76.8	50.0	38.1	14.3	2.4	7.7	12.5	42.3	47.0
75	34.9	16.3	86.8	58.9	46.5	18.6	3.1	10.1	15.5	48.1	55.8
80	44.2	21.1	94.7	68.4	58.9	26.3	4.2	13.7	20.0	58.9	67.4
85	59.1	28.8	90.9	80.3	81.8	47.0	7.6	24.2	36.4	86.4	89.4

Despite the generally much lower share of remaining life years spent living with disease at age 85 compared to age 80, the share

of remaining life years spent living with disease combinations including dementia and stroke actually increases from age 80 to age 85.

Discussion

Across ages 65 and over, CHD caused the most time spent living with disease for Dutch men and osteoarthritis for Dutch women. Of the various co-occurrences of disease, the combination of diabetes and osteoarthritis led to the most time spent living with disease, for both Dutch men and women aged 65 and over.

Disease type and disease prevalence appear to be important factors when determining time spent living with disease by elderly Dutch men and women.

Intuitively, diseases classified as non-fatal will cause elderly men and women to spend more time living with disease and disability and thus require more healthcare resources, especially when these diseases are highly prevalent. Osteoarthritis is not only considered non-fatal but is also highly prevalent among Dutch elderly. Especially for elderly female patients osteoarthritis proved important in terms of the time spent with disease. Eliminating osteoarthritis and other non-fatal disorders would result in savings in hospital care and nursing and residential care facilities. [30]

The fatal disease CHD causing the most time spent living with disease for Dutch men could also be due to the high prevalence of CHD in elderly men, but is also the result of effective treatment,

i.e. the increased healthcare resources allocated to the management of cardiovascular disease in the preceding years. This explanation is in line with the considerable improvement of the survival rate of elderly CHD patients. [31] Also, diabetes is a highly prevalent disease among elderly Dutch people, but not necessarily fatal if controlled properly, which could account for the increased time spent living with disease by elderly diabetes patients. Clearly, the elimination of highly fatal diseases such as CHD but also neoplasms will not only result in a decrease in hospital care costs, but also in an increase in time spent living with the disease, and consequently increasing nursing and residential care facilities costs .

Our results not only clearly indicate important differences between men and women in the impact of specific individual and combined diseases, but also clear differences in their impact by age across the remaining life course at age 65. The time Dutch elderly men spend with either diabetes, CHD or osteoarthritis increases progressively with age, and similarly for Dutch elderly women with osteoarthritis. The various cancers, stroke and dementia, however, do not show the same increasing trend of disability over the life course of elderly women. This clearly indicates that specific single diseases affect elderly men and women differently at different phases in the life course in terms of the time spent living with disease, and consequently, their potential disability and

quality of life. These important differences need to be considered when planning for healthcare and when designing interventions.

As far as multi-morbidity is concerned our results indicate that both diabetes and osteoarthritis can be considered non-fatal diseases and the combination of these two diseases can increase the time spent with disease. Clearly, as far as the effect of multi-morbidity on morbidity is concerned, the non-fatal combination of diabetes and osteoarthritis significantly reduces the disability-free period elderly men and women will enjoy.

The multi-morbid disease combinations which include dementia and stroke appear to be particularly 'oldest old' problems, since they increase the time men and women spend with disease in the 80-84 and 85+ age groups. Oostrom et al. have shown that individuals suffering from multi-morbidity receive more face-to-face and telephone consultations with general practitioners, more minor operations, increased use of prescription medication, more home visits and more referrals to specialized care. [32] People with multi-morbidity may be receiving improved treatment of their known conditions, which might also result in early detection of additional diseases, increasing the survival rate of elderly with multi-morbidity and extending the time spent with disease.

We infer that, aside from the effects on health resource utilization, elderly people with multi-morbidity may also be receiving better

management of their multi-morbid conditions because they use healthcare services more frequently, effectively altering their disease progression and postponing mortality. [33]

Since the prevalence rates of multi-morbid disease are not readily available it is uncertain whether and to what extent the prevalence rates of multi-morbid diseases contribute to the time elderly Dutch people spend with disease. However, it follows our choice to combine transition rates to estimate multi-morbid conditions that we should assume that the prevalence of diseases and the combinations thereof proportionally affect the time spent with disease.

Understanding the effects of multi-morbid diseases on the elderly male and female population could help decision-makers plan appropriate pro-active and timely interventions early in life to negate the negative effects of multi-morbidity in later life

In sum, information from studies like ours provide an indication for sex- and age-specific interventions aimed at the identified individual and combined diseases that cause the most time spent living with disease by age and sex, with as the ultimate aim to decrease disability across the remaining life course of the elderly. Identifying and acknowledging the effects of specific disease on elderly disability is only the first step in a remedial process. Conceivably diseases like diabetes, osteoarthritis and CHD can be cost-effectively managed or even avoided by altering unhealthy lifestyle choices, i.e. doing exercise or by making healthy dietary

choices. Identifying and understanding the social, cultural and economic barriers that prohibit individuals from making or adhering to healthy lifestyle choices, is however essential as well to address the disability associated with specific diseases. [34] Educating health care services regarding important elderly disease interactions and their implications can enhance the effectiveness of interventions to diminish disability. [35]

Strengths and limitations

A multi-state life table approach was used in this study to provide an overview of the disability caused by disease and multi-morbidity. A strength of this approach is the use of data to provide a prospective view on disease progression and disability projections. Although the use of combined transition rates to simulate multi-morbid conditions is a simplification of the multi-morbidity interactions, and 2007 data was implemented in this study, the results of this study are supported by subsequent studies, making the results significant and contributing to the expansion of knowledge in this research domain. [36]

Firstly, the impact of the results can be substantial if utilized by clinicians and other stakeholders, along with results from similar studies within the healthcare sector to plan cost-effective interventions for the current elderly population. Preventive strategies for specific diseases, as indicated by our results, can provide better disability outcomes for the elderly and even delay the onset of disability. Secondly, studies like ours can assist

decision-makers with difficult health resource allocation decisions for future elderly populations.

Understanding how elderly men and women within defined age groups will be affected by disease and multi-morbidity is a valuable tool to provide effective and relevant healthcare services to the elderly.

Conclusions

Specific single and multi-morbid diseases affect elderly men and women differently at different phases in the life course in terms of the time spent living with disease, and consequently, their potential disability. Disease prevalence, disease type and disease interactions are important factors in this regard.

Cost effective interventions and specialized treatment regimens aimed at addressing specific diseases with a high prevalence and multi-morbidity could increase elderly people's quality of life, while reducing disability and healthcare costs for the elderly population.

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Chapter 4

Functional health state description and valuation by people aged 65 and over; a pilot study

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Abstract

Background: Assessing quality of life among the elderly is a complex and multifaceted issue. Elderly people might find valuing and describing their personal experience of quality of life (QoL) demanding and cumbersome. This study therefore sought to determine the feasibility of administering two questionnaires in two samples of elderly people. **Methods:** A preference-based instrument (EQ-5D+C) and a currently achieved functioning questionnaire (CAF) were utilized. Two pilot studies were performed. The first was performed in South Africa (n=30), designed to test whether elderly respondents could complete and understand the two questionnaires and also to indicate which valuation method, visual analogue scale or time trade off they preferred. A second pilot study was performed in the Netherlands (n=30), designed to investigate the use of both questionnaires in determining quality of life and health state valuations in a Dutch sample of elderly. **Results:** Seventy percent of the South African respondents indicated that they preferred the visual analogue scale (VAS) method, when compared to the time trade-off (TTO). In both the South African and the Dutch pilot studies, the respondents, with different dependency levels, were able to use both questionnaires to determine health state descriptions and valuations. When ranking the profiles from fewer to more problems, the EQ-5D+C exhibits a gradual downwards trend, with a maximum of 100 and minimum VAS value of 41. The CAF also

exhibits a gradual downwards trend, with a maximum of 1.00 and minimum VAS value of 36. **Conclusions:** The results indicate that individuals from different parts of the world are able to complete, describe, and value the questionnaires. It is our recommendation that a comprehensive study should be done, which includes both the EQ-5D+C questionnaire and the CAF questionnaire, since the two questionnaires have proven to be feasible in providing information on quality of life and well-being of elderly people.

Background

Aging is a progressive process of deterioration, comprising physical and mental domains. It constitutes loss of ability to maintain and function at previous levels of achievement. Moreover, aging is a personal process that includes both positive and negative experiences. [1] Quality of life (QoL) is one popular outcome measurement used in assessing the effects of aging on what people judge to be important in their lives. It is, however, a contentious subject, since some are of the opinion that i) the elderly population should generate the health descriptions and valuations relating to QoL, while others consider that ii) the general population should provide these health descriptions and valuations. [2-4] Furthermore, the methods and procedures used to determine QoL have yet to be standardized, thus raising issues of the accuracy and applicability of elderly health state descriptions and valuations. [5, 6]

A common method is to use a generic classification system such as the EQ-5D to value and describe health status. [7] Typically, the EQ-5D describes health status in terms of health-related quality of life (HRQoL) domains: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. [8] Despite its many advantages, some concerns have been raised with regard to its use among the elderly. One of the concerns that has been raised is that it may be insufficiently responsive to elements of quality of life and well-being. [9] Applying a totally different conceptual framework such as the capability approach [10] might prove to be a very effective way of defining actual disability, as well as for investigating the valuation of functioning as disability continues. [11] An instrument like the EQ-5D incorporates HRQoL to a large extent into the valuation and descriptive capacity, while the capability approach incorporates non-health aspects such as attachments, role, security, control, and enjoyment, which will influence health and, ultimately, overall well-being. [12, 13]

It has been suggested that the notion of disability and loss of functioning might specifically apply to the elderly as this process is to some degree linked to chronological age and tends to evolve slowly. [14] The functioning of the elderly might largely depend on their acquired lifetime personal, social, and financial assets. [14, 15] Previous studies have shown that a generic preference-based questionnaire, like the EQ-5D, and a functioning questionnaire provide complimentary information on quality of life. [16] It is, however, still uncertain which domains and dimensions of the

questionnaires overlap and to what extent the domains would be double-counted using the two instruments. [17]

The present pilot study aimed to determine the feasibility of two distinct components. First, our aim was to determine which of the two methods for elucidating health-state valuations would be appropriate for the elderly, that is, whether to use a visual analogue scale (VAS) or apply a Time Trade Off method (TTO). Second, we wished to study the feasibility of administering the EQ-5D+C and a generally accepted functioning questionnaire (CAF) to elderly people both from South Africa and the Netherlands.

Methods

A pilot study was performed with two different samples. The first sample was recruited among South African home-dwelling elderly, 65 years and older. The South African elderly participants were asked to complete health-state descriptions and valuations in a recently developed Currently Achieved Functioning questionnaire (CAF) and the EQ5D+C, [18] in order to determine the feasibility of using these questionnaires in an elderly population.
The results of the South African study were reflected upon, and subsequently a second pilot study was performed in the Netherlands. The two questionnaires were evaluated and compared in terms of their suitability for establishing appropriate health state descriptions and valuations for elderly subgroups.

The purpose of the inclusion of these questionnaires was to extract descriptive information regarding the individual domains of the EQ-5D+C and the CAF.

The interviews were performed in accordance with the Helsinki declaration. Ethical approval was granted by the medical ethical testing committee of the University Medical Center Groningen, ethics number M11.098466 (Appendix A).

The UMCG ethical testing committee found that according to medical ethical law the pilot study is not regarded as a study involving significant intervention in human beings. The pilot study is also part of a PhD project, the major part of which will be performed in the Netherlands; therefore, no additional ethical approval was sought in South Africa.

Written consent was however obtained from each respondent who agreed to take part in the study.

Questionnaires

Currently Achieved Functioning (CAF) questionnaire

The Currently Achieved Functioning questionnaire was developed to investigate the achieved functioning and not the functional aspirations or capabilities of the elderly respondents. The CAF questionnaire included the attachment, enjoyment, security, role, and control attributes, with five response categories possible. Inspiration for the development of the CAF came from the work performed by Grewal and colleagues. [19] They embarked on a 2-

stage analysis, first, to determine factors that contribute to the quality of elderly informants' lives and, second, to identify the attributes of quality of life. From this study, 5 attributes emerged: *Attachment, Enjoyment, Security, Role, and Control.* Appendix B summarizes the aspects that contribute and determine these attributes.

Coast and colleagues investigated this matter further by doing qualitative and quantitative work on these five attributes. [20] The qualitative work focused on the design of a measurement instrument, while the quantitative work focused on the validation of the measurement instrument. Ultimately, an instrument to determine the effect of health and social care interventions was presented, while mentioning the potential of the instrument in the economic evaluation of interventions. [20]

The work performed by Grewal and colleagues to determine qualitative attributes important to the elderly was utilized, since these attributes fit into the theory of the capability approach. [19] An extract from the research done by the authors summarizes what was done:

"This paper reports an attempt to determine attributes for a new index clearly focusing on quality of life for older people rather than health or other influences on quality of life. In-depth interviews were conducted with 40 purposively selected informants aged 65 and over in private households to explore their views about what

is important to them in terms of quality of life. Data were analyzed using Framework qualitative analysis. Initial discussions tended to concentrate upon factors influencing quality of life including activities, relationships, health, wealth and surroundings. Further probing and analysis suggested five conceptual attributes: attachment, role, enjoyment, security and control."

Subsequent literature suggests that the non-health-related attributes of attachment – enjoyment, security, role, and control – are unique and can possibly be an alternative or at least contribute to current healthcare interventions designed for the elderly. [21]

The validity of a questionnaire, which includes the attachment, enjoyment, security, role, and control attributes, was also tested in a Dutch setting, with positive results.

The original version of the CAF questionnaire was constructed in English (Appendix C), to be utilized in South Africa, while the English version was translated into Dutch by a specialist translator and one of the authors of the paper (AR).

EQ-5D+C questionnaire

We used an extended version (EQ-5D+C) of the standard EQ-5D that included "cognitive functioning" as an additional attribute. [22] The standard EQ-5D classification system developed by the EuroQol Research Foundation (https://euroqol.org/) describes health status according to five attributes: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each attribute has three levels: "no problems" ("1"), "some problems" ("2"), and

“severe problems” (“3”). Health state descriptions are constructed by choosing one level for each attribute (e.g., the best health state is represented by 11111).

The non-standard EQ-5D+C is similar to the EQ-5D, but with a 3-level cognition attribute added, Appendix D. Of specific relevance to the elderly are health aspects such as vision and hearing, and in particular cognition. [23] [24, 25] The addition of the cognition domain makes the EQ-5D+C of specific importance to the elderly, since aging is to a degree associated with a decline in cognitive ability.

Participants

South African sample

Thirty independent-living elderly individuals from the general population were recruited and divided into to three groups, ten individuals in each group. To be included in the study, participants had to be South African citizens, 65 years and older, and living independently in the Bloemfontein area. Participants were recruited through referrals from elderly community leaders. Potential participants were contacted by telephone and asked if they would be willing to participate. Elderly people willing to participate were recruited, and one-on-one interviews were conducted by a trained interviewer.

Dutch sample

After reflecting on the results of the first pilot study, the decision was made to perform a second pilot study in the Netherlands. The CAF and the EQ5D+C were included in the Dutch pilot study. Thirty elderly were recruited in the Groningen area. Ten were living independently, another ten individuals were semi-independent, meaning they lived independently in the neighborhood of an elderly care center, from which they could receive some help with regard to household chores, dinner, and medical care, and the last group were living in an elderly care center.

Procedure

South African sample

The first group was presented with a questionnaire and was asked to value applicable EQ5D+C target health states, using a Time Trade Off (TTO), Appendix E, and a visual analogue scale (VAS), Appendix F.

Previous studies have shown that TTO techniques place a great cognitive burden on respondents, since they require a high degree of abstract reasoning. [26] Taking this into consideration, the decision was made to utilize a simplified version of the TTO exercise. [27]

In our pilot and feasibility study we therefore switched to a more simplistic (more crude steps) analogue version of the TTO method. The TTO technique required the respondents to value

how much time in health state 111111 (full health) was equivalent to 10 years spent in a target state. Target states represent different levels of decline in HRQoL. Thus, a typical TTO valuation task would involve a hypothetical trade-off between length and quality of life. The TTO process, utilized in our study, provides the elderly respondents with options to choose from, rather than subjectively reasoning and cognitively determining the point of indifference. The chosen TTO exercise provided elderly respondents with a less cognitively burdensome alternative.

The target states were 112112, 212111, 111221, 212121, 133113, 212321, 333211, 323331, and 333333. Only 9 health states were valued for the TTO exercise, since health state 111111 was given as the comparison full-health state.

With regard to the valuation method, we were mainly interested in the feasibility of TTO as a measurement tool in a specific frail elderly population. In line with previous studies our simplified TTO again proved to be too complicated for the majority of respondents, and we subsequently omitted it from the Dutch sample.

The VAS method requires ten health states, 111111, 112112, 212111, 111221, 212121, 133113, 212321, 333211, 323331, and 333333, rated on a visual analogue scale, typically ranging from 0 (worst off) to 100 (full health). They were asked to state which of the two techniques was the easiest to complete in terms of understanding the task that had to be completed, and also the

cognitive burden of the task. Upon investigating the results from the first group, it was decided to continue only with the VAS valuations in group two and group three.

The second group was asked to value and describe ten EQ-5D+C health states using a visual analogue scale. The health states chosen were 111111, 112112, 212111, 111221, 212121, 133113, 212321, 333211, 323331, and 333333.
The third group was asked to complete the questionnaire pertaining to functioning (CAF) that they were currently achieving and also to value ten health states using a VAS: 11111, 21114, 12335, 55555, 11245, 44433, 11122, 11312, 33333, and 33544.

Care was taken to instruct the individuals not to consider their own health when valuing the health states. Instead they had to view the valuation procedure as a task regarding a hypothetical state. It was also made clear that the value of 100 on the VAS (visual analogue scale) would be considered to be the best possible value attainable and that the 0 value would be considered equal to death. The respondents were also instructed to consider the whole scale and not just the marked intervals. [28]

The health states were chosen randomly to reflect the better and worse-off states associated across the spectrum of the two questionnaires. Care was taken, however, to include the health states that represented full health and worst possible health. Only

ten health states per questionnaire were included, so as not to impose a heavy cognitive burden on the elderly respondents. [26]

Dutch sample

The elderly respondents completed the CAF and EQ-5D+C questionnaires and again three subgroups, dependent, semi-dependent, and independent respondents, completed 10 hypothetical health state valuations, for each questionnaire using a VAS.
The health states were identical to the health states that were valued in the South African pilot study. Health states 111111, 112112, 212111, 111221, 212121, 133113, 212321, 333211, 323331, and 333333 for the EQ-5D+C, while health states 11111, 21114, 12335, 55555, 11245, 44433, 11122, 11312, 33333, and 33544 were valued for the CAF questionnaire.

Results

The demographic information on all four groups is presented in Table 1. Seventy percent of the respondents from the SA sample indicated that they preferred the VAS method as compared to the TTO. Exemplary comments from the respondents with regard to the task were:

“The TTO exercise placed a heavy cognitive burden on me”; “I feel the TTO exercise is too difficult to complete”; “the VAS is much

easier to complete"; and "I feel the TTO exercise might not provide accurate results." Based on the fact that respondents complained about and failed to complete the TTO exercise, it was decided to continue using the VAS in group two and group three in the South African study, and in all groups in the Dutch study.

Table 1: Demographic data for all *respondents*

SA pilot study			
Demographic factor	Group 1	Group 2	Group 3
	N=10	N=10	N=10
Male (%)	60	60	40
Age (mean)	71.4	68.6	68
Marital Status			
Single (n)	1	0	0
Married (n)	6	8	9
Widowed (n)	2	2	1
Divorced (n)	0	0	0
Education			
High school (n)	5	1	2
Diploma (n)	1	3	0
Degree (n)	4	5	6
Post degree (n)	0	1	2
Chronic diseases (number)			
1	2	4	5
2	6	5	5
3	3	1	0
Dutch pilot study			
	Independent living	Semi-dependent	Care center
	N=10	N=10	N=10

Age (mean)	73,5	86,4	83,2
Male (%)	40%	20%	20%
Education - Primary school - High School - Diploma University	 0 1 3 6	 5 2 2 1	 6 1 2 1
Percentage of people living alone	40%	80%	90%
Religious background (%)	60%	70%	50%
Total number of chronic disease	11	32	25

Ranking the valuations of the South African EQ-5D+C health states from best to worst health state, illustrated in Table 2, the EQ-5D + C exhibits a gradual downwards trend, with a maximum of 100 and minimum VAS value of 41. The achieved functioning questionnaire also exhibits a gradual downwards trend, with a maximum of 1.00 and a minimum VAS value of 36 (Table3).

Table 2: EQ-5D+C questionnaire ranked health states according to average VAS values

	Dutch Independent	Dutch Semi-dependent	Dutch Dependent	SA Independent
111111	86	78	82	100
112112	78	72	73	81
212111	75	69	74	79
111221	72	69	72	78
212121	72	65	72	77
133113	62	53	68	60
212321	60	62	66	58
333211	55	43	64	56
323331	44	38	63	52
333333	35	37	60	41

Table 3: CAF questionnaire ranked health states according to average VAS values

	Dutch Independent	Dutch Semi-dependent	Dutch Dependent	SA Independent
11111	85	80	77	100
11122	84	74	78	99
11245	65	58	66	90
11312	83	78	75	84
12335	70	58	68	69
21114	78	73	76	67
33333	73	67	68	67
33544	58	57	67	42
44433	58	54	60	41
55555	47	48	57	36

Table 4 summarizes the results from the EQ-5D+C health state descriptions. The South African and Dutch elderly had no difficulty with completing the health state descriptions. The CAF questionnaire also performed adequately, with evident discriminatory power between the functioning dimensions of the questionnaire, Table 5.

Table 4: EQ-5D+C description results

South African pilot study			
n=10	**No.**	**Some**	**Extreme**
Independent living			
Mobility	7	3	0
Self-care	9	1	0
Usual activities	6	4	0
Pain/Discomfort	5	3	2
Anxiety/Depression	9	1	0
Cognition	7	3	0
Dutch pilot study			
Independent living			
n=10			
Mobility	5	5	0
Self-care	10	0	0
Usual activities	8	2	0
Pain/Discomfort	8	2	0
Anxiety/Depression	9	1	0
Cognition	9	1	0
Semi-dependent			
n=10			
Mobility	0	10	0
Self-care	8	0	2
Usual activities	2	6	2
Pain/Discomfort	2	4	4
Anxiety/Depression	9	0	1
Cognition	6	4	0
Care center			
n=10			
Mobility	0	8	2

Self-care	6	2	2
Usual activities	6	1	3
Pain/Discomfort	5	3	2
Anxiety/Depression	9	0	1
Cognition	9	1	0

Table 5: Functioning description results

	South African				
	I have all	**I have a lot**	**I have some**	**I have a little**	**I have none**
Attachment	3	5	1	1	0
Enjoyment	2	5	3	0	0
Security	1	4	4	1	0
Role	2	4	3	1	0
Control	5	3	1	1	0
Dutch independent living					
Attachment	5	3	2	0	0
Enjoyment	3	6	1	0	0
Security	1	3	5	1	0
Role	4	6	0	0	0
Control	5	4	1	0	0
Dutch semi-independent					
Attachment	4	2	3	1	0
Enjoyment	2	2	5	1	0
Security	1	5	2	1	0
Role	3	3	2	2	0
Control	4	2	1	0	3
Dutch dependent					
Attachment	1	3	3	3	0
Enjoyment	2	2	5	1	0
Security	2	2	5	0	1
Role	2	5	2	1	0
Control	4	3	3	0	0

The results of the EQ5D+C subgroup valuations can be seen in Table 2. The EQ-5D+C for the Dutch independent group exhibits a gradual downwards trend, with a maximum of 86 and minimum VAS value of 35. The Dutch semi-dependent group exhibits a gradual downwards trend, with the exception of health state 212321. A maximum of 78 and minimum VAS value of 37 were found. The Dutch dependent group also exhibits a gradual downward trend, with a maximum of 82 and minimum VAS value of 60 found.

As for the subgroups of health state valuations of the CAF questionnaire, the Dutch independent group had a maximum of 85 and a minimum VAS value of 47. The Dutch semi-dependent exhibited an 80 maximum and minimum VAS value of 48. The Dutch dependent group exhibited a maximum of 77 and minimum VAS value of 57.

Discussion

The aim of this study was to investigate which of the two methods, TTO or VAS, which elucidate health state valuations from the elderly, would be appropriate. Also to test the feasibility of using the EQ-5D+C and the CAF questionnaires, in two samples of elderly, in order to report on their own health and QoL.

Participants in the South African part of the pilot study remarked that they preferred the VAS to the TTO method, due to the fact

that the TTO technique was cognitively more burdensome when compared to the VAS technique.

Furthermore, even with the addition of the cognition domain to the EQ-5D questionnaire, the elderly performed the health state descriptions and valuations with ease, using both questionnaires. Both the EQ-5D+C and CAF were able to extract relevant health descriptions and health state valuations. Importantly, the results of the South African study indicate that health state valuations of the EQ-5D+C and CAF questionnaire showed similar patterns. Better health states were valued closer to one, while worse off health states were valued to be closer to zero.

We decided to include both the EQ-5D+C and CAF questionnaires in the Dutch pilot study, since South African elderly were able to complete both questionnaires with ease and since both questionnaires were able to determine health descriptions and health state valuations of the different subgroups.

Valuations of health states for the EQ-5D+C and functioning questionnaire varied between the subgroups of Dutch elderly, and the health state valuation for the two questionnaires returned a high to low pattern. The EQ5D+C and the CAF questionnaire showed very little inconsistency in terms of logical order of the health state valuations. Better health states were valued closer to one, while worse off health states were valued to be closer to zero.

Previous studies have shown that capability-based questionnaires can be used to generate and value health states. [29] However the

results of previous studies still indicate that it would be pertinent to still include a generic preference-based questionnaire, since the degree of double counting and missed health effects is still unclear [17].

Although controversial, the potential exists, however, to use non-health-related questionnaires to measure broader outcomes, while being more sensitive to the effects of the interventions. [30] The results of this study add to the existing literature by indicating that elderly individuals from different parts of the world and with different dependency levels are able to complete, describe, and value the health or capability states included in the questionnaires.

Implications

It is our recommendation that a comprehensive study should be conducted, which includes both the EQ5D+C questionnaire and the CAF questionnaire, since the questionnaires would capture data on individual HRQoL and well-being dimensions. The EQ-5D+C is a version of the well-known and validated EQ-5D questionnaire but, with the inclusion of the CAF questionnaire, a study would provide a more comprehensive measure of elderly quality of life. The questionnaires could identify the subgroups of elderly at risk of diminished HRQoL and well-being. In addition, inclusion of both questionnaires would make it possible to identify domains and attributes that should be addressed in order to maximize elderly QoL and well-being.

Furthermore, such an approach might reveal relevant health state descriptions and valuations, and facilitate the planning of interventions for the elderly population.

Conclusions

The results of the study support the feasibility of the method used in this study. This signals the necessity for a larger study to generate health state valuations and descriptions from the elderly. Valid assessment by the elderly themselves, in the domain of elderly care, QoL, and well-being, should be studied further.

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Chapter 5

Health related quality of life and wellbeing health state values among Dutch oldest old.

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Abstract

Background: Valuing hypothetical health states is a demanding personal process, since it involves the psychological evaluation of hypothetical health states. It seems plausible that elderly individuals will value hypothetical health states differently than the general population. It is however, important to understand the psychological division that oldest old subgroups construct between acceptable and unacceptable health states. This information can produce important evidence regarding wellbeing and disability conceptualization.

Objective: To investigate how Dutch oldest old, conceptualize health related quality of life health states when compared to wellbeing health states. In addition, we aim to compare subgroups, based on dependency classification.

Methods: Ninety-nine elderly living in the Groningen, Hoogeveen and Veendam areas of the Netherlands participated in the study. Respondents were classified into three groups based on dependency levels. The respondents were asked to value hypothetical health states, a generic preference-based HRQoL and a wellbeing instrument, using a visual analogue scale.

Results: All three groups ranked the same health states, from both questionnaires, below the average across the health states. The health related quality of life health states were consistently ranked lower than the current wellbeing health states.

Conclusions: Health state valuations performed by the oldest old indicate that conceptually, respondents view below average health related and wellbeing health states as undesirable. The results indicated that the oldest old do view deficits in health related health states as more important than deficits in wellbeing health states. Since the oldest old performed the valuations, focused interventions to improve below average health related outcomes, might be the most cost effective way to increase oldest old wellbeing outcomes.

Introduction

Different populations may have quite different opinions on the impact of health states, i.e., show considerable variation in the valuation of health states.[1] This notion has resulted in continuous debates on the validity of general societal valuation methods reflecting the 'average' citizens' health state preferences, and whether the valuation process should rather be performed by the specific or affected group of the population instead.[2] Typically health state valuation exercises are utilized to investigate the values patients, the general population or specific groups attach to hypothetical health related quality of life (HRQoL) or wellbeing health states. However, this study was done concerning the descriptive and nuanced experience of aging as described by various elderly contexts and perspectives on health values. [3]

Considering the abovementioned, it seems plausible that certain subgroups of elderly will value hypothetical health states differently than the general population. Interestingly, demographic variables such as age, sex and educational level only partially explain the variance in health state valuations observed.[4] Additional factors such as level of disability, the functional outcome/domain affected, availability of resources and type of disease may all impact on the valuation process.[5]

Moreover, valuing hypothetical health states is an arduous personal process, since it involves a psychological evaluation of hypothetical health states.[6] In the case of the oldest old, typically 80-years and above, age may be a unique modifier of health state valuation. It has been demonstrated that 80+ individuals may be suffering from several chronic diseases, possibly significantly impairing activities of daily living, as well as increasing cognitive impairment. This subgroup might very well value health states differently from their younger elderly counterparts.[7, 8] The current study was however concerned with investigating health state valuations, within oldest old subgroups, based on dependency classification. Dependency classification typically referring to living independently, living dependently with moderate care or living in a nursing home requiring consistent care. The oldest old group, almost without exception, suffers from several ailments and suboptimal health.[9, 10] The question is whether indeed the perceived quality of life falls below the average for the oldest old subgroups. Possibly health states can be identified that are valued

as worse, suggesting that these health states contribute to poorer HRQoL and wellbeing. Implicitly this suggests that if society can define disability and wellbeing in terms of what the oldest old deem as acceptable and unacceptable states of health, treatment guidelines will have to be adapted to accommodate their wishes. Acceptable and unacceptable health states might be different between subgroups and between HRQoL and wellbeing health states, which can further explain the value the oldest old attach to states of health and disability.

To measure HRQoL and wellbeing, several instruments have been developed. The EQ-5D is a well-known and widely utilized instrument that mainly focuses on valuing HRQoL.[11, 12] Another approach was taken in developing a relatively new instruments, focussing on a wellbeing perspective.[13] Typically, these newer instruments are developed to expand HRQoL by including and broadening the health content to produce wellbeing measures. Thus, the concept of health will include and in fact become a more comprehensive concept of capabilities and functionings. Instruments like the ICECAP-O and ASCOT emerged.[14]

The ICECAP-O is an instrument grounded in the theory of the capability approach.

Sen's capability approach describes health as being comprised of both capabilities and functionings.[15] The notion of capabilities and functionings are important, since capabilities refer to the possibilities one can achieve or aspire to achieve. Functionings

refer to actual achievements and accomplishments.[16] While actual achievements are essential to realize health and wellbeing goals, "feeling" capable to achieve and strife for better health might be the first step to actual achievement of the HRQoL and wellbeing goals. Implicitly this suggests that capabilities has a strong psychological component of how people perceive their future quality of life and wellbeing.[6] The valuation of health states is therefore related to acceptable and unacceptable capabilities of the oldest old age groups. Being able to project yourself into the future with a positive view on your health and wellbeing might be important to adapt to a disease-affected life.

Deficits in capability and functionings could have negative repercussions on achieving appropriate health care goals.[17] As with HRQoL, specific diseases will also impact on the capability and functionings impeding individual and societal health care goals.[18] [19] Evidently maintaining personal and health resources is important to achieve relevant health and non-health capabilities and functionings.[20] It is therefore important to understand how oldest old dependency subgroups value HRQoL and wellbeing health states. Understanding the psychological division the oldest old construct between acceptable and unacceptable health states can yield valuable information regarding wellbeing, disability and mortality profiles.[21] Our hypothesis is that the valuations performed by the subgroups of oldest old, will identify HRQoL and wellbeing health states that are subjectively valued as acceptable while other health states are valued as unacceptable.

Objective

To investigate how Dutch oldest old, conceptualize HRQoL health states when compared to wellbeing health states. In addition, we aim to compare subgroups, based on dependency classification.

Methods

Participants and study design

Elderly individuals living in the Northern area of the Netherlands were recruited (Groningen, Veendam, Hoogeveen). The only inclusion criteria specified was that respondents had to be aged 65-years an older. They could be living independently and looking after themselves, living dependently with moderate care from family or a health professional or living in a nursing home requiring comprehensive care from a health professional. Dependency was established by asking the respondents to indicate with which subgroup they identified most. The recruitment process involved a) contacting the elderly via telephone, b) asking whether they would be willing to participate in the study c) checking whether the individual fits the inclusion criteria d) making an appointment with the individuals that fitted the inclusion criteria and e) meeting the elderly participants, at their place or residence, to conduct the interview.

Structured interviews were conducted with a generic preference-based HRQoL instrument, the EQ5D+C and a wellbeing instrument the Currently Achieved Functioning questionnaire

(CAF). The respondents were asked to value hypothetical health states using a visual analogue scale (VAS). Ten hypothetical health states per instrument were presented. The average value were calculated, across the ten health states, for each oldest old subgroup to determine which health states were below the average and possibly deemed undesirable by the elderly subgroups. This was done to investigate how Dutch oldest old subgroups, based on dependency classification, conceptualize HRQoL health states when compared to wellbeing health states. All respondents completed and signed informed consent forms to participate in the study. Ethical approval was obtained from the UMCG ethical committee (Metc 2011/041), regarding the procedures and methods used in this study (reference number M11.098466).

Measures

EQ-5D+C

The EQ-5D+C is a descriptive system whereas for the EQ-5D-3L utility, values are available. The instrument was developed by the EuroQol group and mainly focuses on health related quality of life (HRQoL).The EQ-5D-3L can be extended by adding on a so-called bolt-on domain. The domains included in the EQ-5D+C are mobility, self-care, usual activities, pain/discomfort, anxiety/depression and cognition (cognition being the bolt on here) (http://www.euroqol.org/.[11, 22, 23] For each domain three

possible answer categories exist: 1. no problem, 2. moderate problems, 3. extreme problems.

Currently Achieved Functionings questionnaire (CAF)

The CAF instrument is theoretically embedded in the capability approach.[24] The questionnaire used to assess the feasibility and appropriateness of the capability approach was developed and send out prior to the formal launch of the ICECAP-O questionnaire. We therefore relied on the attributes identified by Grewal et.al, [25] to develop the CAF questionnaire. The attributes, identified in the above-mentioned paper, were utilized to construct a questionnaire related to the concept of capabilities/ functionings. CAF is a preference based instrument, designed specifically for the elderly, with a broader perspective on HRQoL and includes domains like attachment (feelings of love and affection), enjoyment (activities providing joy or pleasure), security (feeling secure when considering health and finances), role (having a purpose) and control (making one's own decisions).[26] Pilot studies have been performed in the Netherlands and in South Africa to test the feasibility and the validity of the CAF questionnaire.[27] From the results of the pilot studies, individuals from different subgroups and even different parts of the world, indicated that they are able to value, describe and complete the CAF questionnaire.

Health state valuation

A visual analogue scale was also utilized for the valuation exercise. The VAS is a vertical line, ranging from zero to 100. Zero on the scale represented the worst imaginable health state while hundred represented the best imaginable health state. Respondents in this study were instructed to value ten hypothetical health states from the CAF questionnaire, using a VAS. The health states chosen were; 11111, 11122, 11245, 11312, 12335, 21114, 33333, 33544, 44433, 55555. One (1) constitute the ability to obtain "all" in the attribute, 2 constitute the ability to obtain "a lot" in the attribute, 3 constitute obtaining "some" of the attribute, 4 constitute obtaining " a little" and 5 constitute obtaining "none" of the attribute. Health state 12335 will therefore constitute; all attachment, a lot of enjoyment, some security, some purpose in life and no sense of control.

Respondents were also instructed to value ten hypothetical EQ-5D+C health states using a visual analogue scale (VAS). The health states chosen were 111111, 112112, 212111, 111221, 212121, 133113, 212321, 333211, 323331, and 333333. One (1) constitutes full health in attribute, 2 constitutes "some" deficits in attribute and 3 constitutes extreme problems in attribute. Health state 212321 will therefore constitute; some problems in mobility, no problems in self-care, some problems in activities of daily living, extreme problems with pain experience, some problems with anxiety and no problems with cognition. The health states, from

both questionnaires, were selected to reflect a representative spectrum of health states from better to worse.

Statistical analysis and calculations

Mean VAS scores for the ten EQ-5D+C and ten CAF hypothetical health states were calculated for the three subgroups, i.e. independent, semi-dependent and dependent. The average converted VAS scores for each health state were calculated. The scores of the health states for each subgroup were then compared and reported. The following formula was used to convert the VAS scores.[28]

VAS value= (VAS score-VAS score$_{(death)}$ /(VAS score$_{111111}$-VAS score$_{(death)}$)

Typically, the converted VAS scores can be utilized to calculate quality adjusted life years (QALY) for a specific group, sample or population.[29] In general terms the QALY is expressed as the value respondents assign to a specific health state, multiplied by the hypothetical length of time spent in the specific state.[29] The QALY therefore provides a single index number that provides the opportunity to compare health outcomes or health care interventions. Our study however focussed on valuations performed by the oldest old to understand the conceptual differences between HRQoL health states when compared to wellbeing health states. We focused on the descriptive statistics, converted VAS values and average converted VAS values. Best to worse ranking exercises were applied to the health states, since

the objective of this study was to investigate the subjective values that oldest old subgroups place on HRQoL and wellbeing health states. We utilized the converted VAS values to identify which health states are below the average values of the converted VAS scores. Ranked health states below the average values of the converted VAS scores were also compared between the EQ-5D+C and the CAF questionnaire.

Results

The total sample of the study comprised of 99 respondents, 29 living independently, 30 living semi-dependently with moderate care and 40 living in a nursing home requiring consistent care. Table 1 indicates the socio-demographic variables for the three groups. Noteworthy observations are that the majority of the respondents were female, with an average age of 80-years and above for all three groups. Only the dependent group reported that they have more than two people in the household. The disease profiles for all three groups appear to be similar, with the exception of the dependent elderly, reporting higher prevalence of heart disease and stroke but with fewer psychological disorders.

Table 1: Socio-demographic and disease variables

	Dependent n = 40	Semi-dependent n = 30	Independent n = 29	p-values	significance
Age Mean [Range]	87 [81-93]	83 [75-89]	80 [69-87]	ns	
Female, n (%)	33(83)	21(70)	22(76)	ns	
Education					
Primary n (%)	13(33)	12(40)	10(34)	ns	
Secondary	9(23)	8(27)	10(34)	ns	
Vocational training	13(33)	8(27)	5(17)	ns	
Higher education/ University	5(13)	2(7)	3(10)	ns	
Other			1(3)	ns	
Spiritual interest Yes	21(53)	16(53)	13(45)	ns	
Number of people in household N					
(%)	12(30)	17(57)	20(69)	ns	
1	11(28)	13(43)	9(31)	ns	
2	17(43)	0	0	< 0,01	dependent/independent and dependent/semi-dependent
3					
Number of diseases N (%)					
0	4(10)	5(17)	3(10)	ns	
1	12(30)	6(20)	8(28)	ns	

2	9(23)	6(20)	5(17)	ns	
3	8(20)	8(27)	7(24)	ns	
4	3(8)	2(7)	2(7)	ns	
5	4(10)	3(10)	3(10)	ns	
6	0	0	1(3)	ns	
Disease type N					
(%)	3(8)	2(7)	5(17)	ns	
COPD	14(35)	2(7)	3(10)	< 0,01	dependent/independent and dependent/semi-dependent
Heart disease	25(63)	18(60)	17(59)	ns	
Hypertension	8(20)	4(13)	1(3)	0,06	dependent/independent only
Stroke	3(8)	3(10)	4(14)	ns	
Kidney/Gall stones	1(3)	0	1(3)	ns	
Kidney disorder	6(15)	9(30)	5(17)	ns	
Diabetes	20(50)	16(53)	17(59)	ns	
Joint disorders	1(3)	1(3)	1(3)	ns	
Epilepsy	3(8)	4(13)	5(17)	ns	
Cancer	2(5)	6(20)	9(31)	ns	
Psychological disorder					

ns: not significant (significance level = < 0,05)

Health related quality of life valuations

The dependent, semi-dependent and independent elderly groups awarded state 111111 with the maximum score of 1.00. The dependent, semi-dependent and independent groups all ranked the following health states below the average across the health states: 133113; 212321; 333211; 323331; 333333. Upon investigation of the EQ-5D+C subgroup valuations (table2), it

became clear that the dependent elderly group valued all the health states higher, with the exception of health state 212321. The results from the EQ-5D+C valuations exercise, indicates that the respondents also valued better health states closer to one and worse health states closer to zero.

Table 2: EQ-5D+C valuations of the oldest old subgroups

Health states	Dependent	Semi-dependent	Independent
111111	1.00	1.00	1.00
112112	0.83	0.75	0.77
212111	0.82	0.76	0.77
111221	0.76	0.74	0.71
212121	0.77	0.70	0.70
133113	**0.54**	**0.47**	**0.49**
212321	**0.49**	**0.48**	**0.52**
333211	**0.44**	**0.43**	**0.41**
323331	**0.37**	**0.37**	**0.34**
333333	**0.24**	**0.20**	**0.20**
Average across health states	0.63	0.59	0.59

Wellbeing valuations

The CAF valuations indicate that the respondents valued better health states closer to one and worse health states closer to zero (Table 3). The dependent, semi-dependent and independent

elderly awarded health state 11111 a value of 1.00. In the dependent, semi-dependent and independent groups, a similar trend is evident. All the groups ranked the same health states, 11245; 12335; 33544; 44433 and 55555, below the average, across all the health states. Additionally, the dependent group valued health state 33333 below the average across the health states. The dependent group valued 12335; 33544; 44433 and 55555 health states the highest, compared to the other two groups.

Table 3: CAF valuations of oldest old subgroups

Health states	Dependent	Semi-dependent	Independent
11111	1.00	1.00	1.00
11122	0.92	0.95	0.94
11245	**0.62**	**0.66**	**0.60**
11312	0.87	0.89	0.87
12335	**0.74**	**0.73**	**0.69**
21114	0.84	0.82	0.80
33333	**0.73**	0.76	0.75
33544	**0.58**	**0.53**	**0.49**
44433	**0.63**	**0.56**	**0.50**
55555	**0.42**	**0.41**	**0.33**
Average across health states	0.74	0.73	0.70

Health related vs wellbeing valuations

Upon comparison of the EQ-5D+C and CAF health states below the subgroup average, it becomes apparent that the EQ-5D+C health states were consistently ranked lower than the ranked CAF health states. Across the subgroups, the worst health state in the CAF valuations, 55555, is valued considerably higher than the worst EQ-5D+C, 333333, health state. However, in both the EQ-5D+C and CAF, all three subgroups valued the best health state with the highest value possible: 1.00

Discussion

Valuing well-being health states relates to the fact that factors like age, disability and dependency affects how elderly value health states. [5, 30]

This study investigated Dutch elderly health state valuations, using both a utility based and capability based questionnaire and reported on the implicit nature of how the oldest old subgroups conceptualize HRQoL health states when compared to wellbeing health states.

The first important result from the EQ-5D+C questionnaire indicates that all three subgroups ranked the bottom five-health states, 133113, 212321, 333211, 323331 and 333333, below the average scores of the subgroups. This is an important finding, since this indicates that, subjectively, the participants view the lowest five-health states as undesirable or unacceptable. Implicitly

this suggests that the oldest old might deem the health states above the subgroup average as acceptable and part of the process of aging. Conceptually, this has implications for current practice guidelines when defining disability within groups, individuals or populations. If individuals, within a certain group, can agree that specific deficits in health is acceptable, then treatment guidelines for those health states should be adjusted accordingly. Suggesting that the concept of disability within a group like the oldest old should be re-examined and redefined to include the views of the oldest old. [3]

The dependent elderly valued the majority of the health states the highest of the three groups, despite the reality of decline and higher prevalence of stroke and heart disease in this subgroup of elderly.[31] This result reinforces the idea that being dependent does not mean that the elderly are experiencing negative sentiments regarding future health and quality of life. The dependent elderly still place a higher valuation on worse off health states, when compared to the other two groups. A possible explanation can be the fact that the dependent elderly has adapted to the “new” level of disability and view worse off health states better than the semi-dependent and independent groups.[32] This allows the dependent elderly to have an optimistic view on future health capabilities.

As for the CAF valuations, all the subgroups ranked health states 11245, 12335, 33544, 44433 and 55555 equal to or below the

subgroup average. As with the EQ-5D+C health states, this is noteworthy, since this suggest that subjectively, the participants view health states 11245, 12335, 33544, 44433 and 55555 as undesirable, while the remaining health states might be viewed as acceptable. If certain health states are deemed acceptable, while some are deemed unacceptable, this should result in the adjustment of disability threshold values and treatment guidelines.[33]

The dependent elderly valued the health states the highest of the three groups. Here again it is clear that being dependent does not mean that the elderly are experiencing negative sentiments regarding their future functionings and well-being. Adapting to disability allows the dependent elderly to be optimistic about worse off non-health related health states.[34]

Secondly, the subgroup average values across the health states of the CAF health states are higher than the health states of the EQ-5D+C questionnaire. In addition, comparing the below average ranked health states of the EQ-5D+C and CAF, shows that the oldest old, do view deficits in health related health states as more important than deficits in wellbeing health states. This concept is supported by a previous study indicating that when people value EQ-5D health states, they already consider the effects the health deficits will have on non-health aspects of their lives.[6] It would appear that EQ-5D+C health states refer to

physical, mental and cognitive decline, which the oldest old individuals may recognize as part of the aging process, [32] but conceptually the oldest old also realize the effects these health deficits will have on wellbeing.[35] This construct, the oldest old do view deficits in EQ-5D+C health states as more important than deficits in CAF health states, might be of importance when achieving acceptable wellbeing is important to the elderly. The pathway to achieve the social support of friends and family and still have control over daily and future decisions, [36] might be to preserve health related domains like mobility, cognition and to reduce pain experience and depression. We consider the results obtained very relevant yet some limitations of the study should be mentioned.

The limitations of the study are as follows: Firstly, the CAF questionnaire is a conceptual questionnaire and not yet widely applied and utilized in subsequent studies. The pilot studies performed however confirmed the feasibility of the CAF questionnaire for use in our study. Secondly, not all participants adhered to the definition of oldest old, although the average age of the three groups were all 80-years and above.

Finally, since this study was performed in the Northern part of the Netherlands and with a relatively small number of respondents, future studies must include more respondents and include more Dutch regions to further support the conclusions made by this study. Amid these limitations, the strength of this study is

significant since important findings were substantiated, and new associations were found. Another strong point may be the fact that the results are in line with previous research and evidence and that the associations investigated are quite robust.

The results from this study reinforce the results from previous studies indicating that a capability based instrument, like the CAF, not only provides complimentary information to the EQ-5D+C, but elderly subgroups, also value similar hypothetical health related and wellbeing health states as unacceptable. .

Conclusions

Health state valuations performed by the oldest old indicate that conceptually, respondents view below average health related and wellbeing health states as undesirable. The results also indicate that the oldest old, do view deficits in health related health states, as more important than deficits in wellbeing health states. Possibly, due to the fact that preservation of function is deemed important by the oldest old. This suggests that focused interventions to improve or avoid below average health related outcomes, like limited mobility, pain and cognitive impairment might be the most cost effective way to increase oldest old wellbeing outcomes.

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Chapter 6

Functioning and quality of life in Dutch oldest old with diverse levels of dependency

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Abstract

Background: Frequently, a questionnaire like the EQ-5D is applied to investigate elderly health related quality of life (HRQoL), but current literature suggests that inputs that go beyond these traditional health aspects might be of importance. The capability approach is a different method, which integrates several non-health related factors to define wellbeing of the oldest old**. Objective:** We propose to investigate the differences in oldest old functionings and quality of life (QoL), given different levels of dependency, using both a utility (EQ5D+C) and capability based (CAF) questionnaire. **Methods:** We interviewed 99 Dutch elderly, living in the Groningen, Veendam and Hoogeveen area. The average age of the elderly was 80-years, either living independently; still looking after themselves; living semi-dependently with moderate care or living in a nursing home requiring consistent care. **Results:** The utility score for the dependent group is the lowest of all three groups, across the diseases investigated in this study. The respective average utility scores calculated for the dependent, semi-dependent and independent subgroups were 0.56 (SD+- 0.10); 0.84(SD+- 0.11) and 0.69(SD+- 0.13). Mobility and pain were reported to be the major domains where problems appeared across the three groups.. Additionally, dependent elderly experience deficits in the role and control functionings while the other two subgroups experience deficits in pleasure and security. **Conclusions:** The results suggests that it is important to take note of the achievability

of functionings and HRoQL, in addition to care dependency, to obtain QoI and wellbeing outcomes for the oldest old.

Introduction

Elderly quality of life is a multidimensional concept which includes psychological, physical and social dimensions. [1-3] Apparently, elderly health care poses a unique challenge with various social, psychological and physical problems occurring at advanced age. [4, 5] Notably, two thirds of Europeans aged over seventy five are reporting suboptimal health status.[6] It is therefore of the utmost importance to address elderly functioning and disability in elderly health care and treatment options. Chronic illness, co-morbid disease, income, individual resilience and social support are factors influencing the wellbeing of the general population. It is however clear that factors like self-efficacy, perceiving life as meaningful and manageable are important factors to consider when determining elderly HRQoL and functionings. [1, 7] These factors become increasingly pertinent in the elderly, yet it remains uncertain how these factors influence the wellbeing of the oldest old, compared to the general population. [8]

Frequently, a questionnaire like the EQ-5D is applied to investigate health related quality of life (HRQoL). Importantly, this instrument was developed with a typical adult middle aged population in mind rather than an elderly individual. Therefore,

quite possibly the available instruments are inappropriate for the elderly as standard instruments as these do not include the non-health related factors mentioned above. [9] HRQoL is however a generic issue, which should ultimately capture the relevant issues for any individual regardless of age, gender and cultural background.

To resolve the current mismatch between instruments' constructs and the target population the capability approach may provide an alternative. The approach enables including various non-health related factors that determine wellbeing of the elderly.[10] Functionings is a part of the capability approach and focuses on what people actually achieve with the resources at their disposal.[11] However, disease impairs an individual's ability to achieve functionings thereby reducing an individual's QoL. Subsequently, a state referred to as actual disability is induced.[12] Previous studies have shown that functionings instruments, like the ICE pop CAPability measure for older people (ICECAP-O), capture a broader range of benefits. Particularly, for the elderly an important part of the objective of interventions is to generate value beyond HRQoL. [13, 14] Indeed, studies have indicated that there is a causal relationship between changes in functional status and disease status with self-rated health.[15].

Therefore, the importance of understanding how elderly health profiles, based on level of dependency, disease prevalence and resource availability, affect elderly quality of life (QoL) and functionings is obvious for considered health care and treatment

choices. Each chronic disease has its own pathway of decreasing Qol. However resource availability significantly affects QoL and the functionings of the elderly.[16, 17]

Resources can be socio-demographic in nature: education, income, living arrangements to personal characteristics and social support.[12]. Resources allow individuals to convert unique utility and capability profiles into effective self-management strategies. [18]

Importantly, current literature suggests that additional resources like home care, personal care workers, physiotherapy and occupational therapy can improve HRQoL and well-being outcomes. [19] Thus, identifying what the elderly think about prioritization, resource allocations and successful aging might be of paramount importance when the aim is to adapt health care services according to the views of the elderly.[20, 21]

Since there is evidence to suggest that the capability approach will provide complementary information regarding QoL, [13] the current study will focus on elderly QoL, given different levels of dependency and the effects of prevalent chronic diseases, using an integrated utility and capability based approach. It is hypothesized that certain diseases and multi-morbidity will cause larger decline in utility and capability and will ultimately have an implicit effect on the achievement of functionings. [22] In addition, we hypothesize that the absence or presence of certain resources are a paramount factor to include in QoL considerations, since

resources can be mediating factors that determine the difference between effectively managing a disease and developing potential disability.

Methods

Subjects and study design

University Medical Centre Groningen (UMCG) has a special interest in healthy aging. As part of this particular focus elderly in the local, Northern, part of the Netherlands (Groningen, Veendam and Hoogeveen) were invited to participate in the study. The recruitment process involved telephonically contacting elderly and asking whether they would be willing to participate in the study. Inclusion criteria were aged 65-years and older fulfilling one of the following living arrangements:

Living independently; still looking after themselves; living semi-dependently with moderate care (still able to perform instrumental tasks of daily living with some help for another person) and living in a nursing home requiring consistent care. No specific exclusion criteria were implemented. This is due to the fact that the aim of the study was to include a broad range of respondents with a wide variety of health and non-health deficits, to fully understand the problems the sample of oldest old Dutch respondents face.

Demographic information of the respondents was gathered. The interviewer recorded the number of chronic disorders, the level of education, number of people in a household, spiritual interests

and multi-morbidity of the respondents via self-report. Spiritual interests were determined by asking whether the respondents viewed themselves as being religious, with a simple yes or no answer. Respondents were asked to report any chronic disorders, read from a list by the interviewer, which included prevalent disorders.

The EQ-5D+C and CAF questionnaires were used during structured interviews to retrieve the data. Two pilot studies were performed to test the feasibility of the study. Details of the pilots were published and are available in print. [23] The results from the pilots indicated that individuals from different parts of the world are able to complete, describe, and value the EQ-5D+C and CAF questionnaires. We concluded that since the two questionnaires have proven to be feasible in providing information on quality of life and well-being of elderly people, a comprehensive study should be done, which includes both the EQ-5D+C and the CAF questionnaire.

All respondents completed and signed informed consent to participate in the study. Ethical approval was obtained from the UMCG ethical committee (Metc 2011/041), regarding the procedures and methods utilized in this study. Reference number M11.098466.

Problems reported as limitations in utility and functionings were regarded as respondent's inability to perform at, or achieve relevant QoL and wellbeing levels. The concept of health and disability, as described in this study, further suggests that

resources is a key factor to consider when determining an individual's disability status. When compared to respondents who were achieving QoL and wellbeing thresholds set by the elderly respondents, the importance of the reported problems becomes relevant. Non obtainment of utility and functionings possibly translates into poorer QoL and actual disability for individuals with sub-optimal performance. This study therefore to a large extent focuses on the problems reported by the independent; semi-dependent and dependent elderly. Additionally, we gathered socio-demographic information, which may modify QoL and wellbeing.

The EQ-5D+C questionnaire

The EQ-5D+C is a utility instrument, developed by the EuroQol group and mainly focuses on health related quality of life (HRQOL). Domains included in the EQ-5D+C are mobility, self-care, usual activities, pain/discomfort, anxiety/depression and cognition. This questionnaire is an updated version of the EQ-5D and includes a sixth domain, cognition. [24, 25] For each domain three possible answer categories exist: 1. no problem, 2. moderate problems, 3. extreme problems. This part of the EQ-5D+C is used to describe the actual health state of the elderly respondents.

An extract from previously published work, describes the validity and applicability of the EQ-5D+C:[23] "We used an extended version (EQ-5D+C) of the standard EQ-5D that included "cognitive

functioning" as an additional attribute. The standard EQ-5D classification system developed by the EuroQol Research Foundation (https://euroqol.org/) describes health status according to five attributes: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each attribute has three levels: "no problems" ("1"), "some problems" ("2"), and "severe problems" ("3"). Health state descriptions are constructed by choosing one level for each attribute (e.g., the best health state is represented by 11111).

The non-standard EQ-5D+C is similar to the EQ-5D, but with a 3-level cognition attribute added. Of specific relevance to the elderly are health aspects such as vision and hearing, and in particular cognition. The addition of the cognition domain makes the EQ-5D+C of specific importance to the elderly, since aging is to a degree associated with a decline in cognitive ability." The proportion of respondents reporting some problems and extreme problems were calculated, within each subgroup, in each of the EQ-5D+C domains. The EQ-5D+C/utility scores for each subgroup, type of disease (hypertension, heart disease, diabetes, psychological disorder, joint disorder) were calculated. Since an algorithm for the EQ-5D+C questionnaire or ICECAP-O questionnaire is lacking for the Dutch population the overall utility scores were calculated using the Dolan (UK) EQ-5D algorithm. The later does presently not include the cognition domain.[26] The authors however included the cognition domain to evaluate if the subgroups of elderly show differences between cognitive abilities,

when evaluating their own health descriptions. Typically algorithms are used to provide a value which represents the utility assigned to a health/disease state by a certain group of respondents. These utility values can be used to calculate quality adjusted life years (QALY's) for the respondents providing the utility scores. In this paper, scores below the subgroup mean were regarded as contributing to poorer QoL. [27]This was done to explicitly focus on the factors significantly influencing elderly QoL. SPSS version 16 was used to perform the sum score calculations. All the other calculations were performed using Microsoft Excel.

Currently achieved functionings questionnaire (CAF)

The Currently Achieved Functionings questionnaire is theoretically rooted in the capability approach.[10] The capability approach promotes the idea that every individual strives to be or do something. The two major components of this approach, functionings and capabilities, are one's achieved doings and beings (functionings) and one's ability to achieve certain functionings (capabilities).[28] Grewal *et. al* embarked on a 2-stage analysis to firstly determine factors that contribute to the quality of elderly informant's lives and secondly to identify attributes of quality of life.[29] From this study five attributes emerged; *Attachment, Enjoyment, Security, Role and Control.* Appendix A summarizes the aspects that contribute and determine these attributes.

Coast *et al.* investigated this matter further by doing qualitative and quantitative work on these five attributes.[30] The qualitative work focused on the design of a measurement instrument, while the quantitative work focused on the validation of the measurement instrument. Ultimately an instrument to determine the effect of health and social care interventions was presented while mentioning the potential of the instrument in economic evaluation of interventions.[30]

The currently achieved functionings questionnaire used the five attributes to investigate elderly functionings. Pilot studies were performed in the Netherlands and in South Africa to test the feasibility and the validity of the currently achieved functionings questionnaire. From the results of the pilot studies individuals from different subgroups, and even different parts of the world, indicated that they were able to complete, describe and value the currently achieved functionings questionnaire.

Statistical analysis

Statistical analysis performed on the results included determining utility scores of the five most prevalent diseases (Fig 1), using the Dolan (UK) EQ-5D algorithm.[26] Although the algorithm do not include the cognition domain, the addition of the cognition domain can provide valuable descriptive information on the cognitive status of the respondents. Typically, this rating scale is used to

measure general health. Scores closer to 1 indicates better HRQoL and scores closer to 0 indicates worse HRQoL.

Statistical analysis was performed on the descriptive data obtained from both questionnaires. Respondents reporting problems in domains or attributes, of both questionnaires, were evaluated to determine the percentages of respondents reporting problems in achieving HRQoL and wellbeing outcomes. The results of this descriptive analysis is presented in Fig 2 and Fig 3 respectively. Descriptive statistical analysis was performed on the demographic data (Table1) and the p-values calculated using the Chi square test.

Results

Respondents

The total sample of the study comprises of 99 respondents. The average age of the elderly was 80-years, 29 living independently, still looking after themselves, 30 living semi-dependently with moderate care and 40 living in a nursing home requiring consistent care. Table 1 describes the socio-demographic variables for the three groups. The majority of the respondents were female. Only the dependent group reported that they had more than two people in the household. The disease profiles for all three groups appear to be similar with the exception of the

dependent elderly reporting higher prevalence of heart disease and stroke, and fewer psychological disorders.

Table 1: Socio-demographic and disease variables

	Dependent n = 40	Semi-dependent n = 30	Independent n = 29	p-values	significance
Age Mean [Range]	87 [81-93]	83 [75-89]	80 [69-87]	ns	
Female, n (%)	33(83)	21(70)	22(76)	ns	
Education					
Primary n (%)	13(33)	12(40)	10(34)	ns	
Secondary	9(23)	8(27)	10(34)	ns	
Vocational training	13(33)	8(27)	5(17)	ns	
Higher education/University	5(13)	2(7)	3(10)	ns	
Other			1(3)	ns	
Spiritual interest Yes	21(53)	16(53)	13(45)	ns	
Number of people in household N (%)					
1	12(30)	17(57)	20(69)	ns	
2	11(28)	13(43)	9(31)	ns	
3	17(43)	0	0	< 0,01	dep/indep and dep/semi
Number of diseases N (%)					
0	4(10)	5(17)	3(10)	ns	
1	12(30)	6(20)	8(28)	ns	

2	9(23)	6(20)	5(17)	ns	
3	8(20)	8(27)	7(24)	ns	
4	3(8)	2(7)	2(7)	ns	
5	4(10)	3(10)	3(10)	ns	
6	0	0	1(3)	ns	
Disease type N (%)					
COPD	3(8)	2(7)	5(17)	ns	
Heart disease	14(35)	2(7)	3(10)	< 0,01	dep/indep and
Hypertension	25(63)	18(60)	17(59)	ns	dep/semi
Stroke	8(20)	4(13)	1(3)	0,06	dep/indep only
Kidney/Gall stones	3(8)	3(10)	4(14)	ns	
Kidney disorder	1(3)	0	1(3)	ns	
Diabetes	6(15)	9(30)	5(17)	ns	
Joint disorders	20(50)	16(53)	17(59)	ns	
Epilepsy	1(3)	1(3)	1(3)	ns	
Cancer	3(8)	4(13)	5(17)	ns	
Psychological disorder	2(5)	6(20)	9(31)	ns	

ns: not significant (significance level = < 0,05)

EQ-5D+C domain scores and utility scores

The respective average utility scores calculated for the dependent, semi-dependent and independent subgroups were 0.56 (SD^{+-} 0.10); 0.84 (SD^{+-} 0.11) and 0.69 (SD^{+-} 0.13).

Fig 1 presents the utility scores calculated for respondents suffering from psychological disorders, heart disease, joint disorders, diabetes and hypertension. The authors included these

five diseases, as these were the most prevalent in the sample of elderly.

The utility scores calculated for the dependent, semi-dependent and independent subgroups suffering from psychological disorders, heart disease, joint disorders, diabetes or hypertension are all below the average utility scores of the respective subgroups.

The utility score for the dependent group is the lowest of all three groups, across all diseases investigated in this study. The utility scores for the semi-dependent group are the highest of the three groups, across diseases. Notably the semi-dependent and independent groups with joint disorder returned the lowest utility scores of 0.80 and 0.57 respectively. In the dependent group, however, psychological disorder resulted in the lowest utility score of 0.11. This result was due to the fact that only two respondents reported psychological disorder with apparently very low scores. Excluding this result would move heart disease into the lowest position for the dependent elderly.

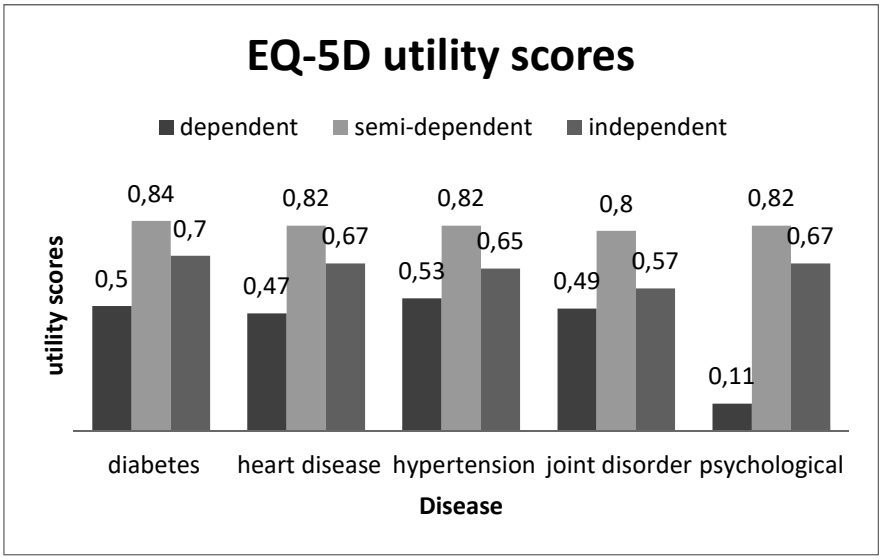
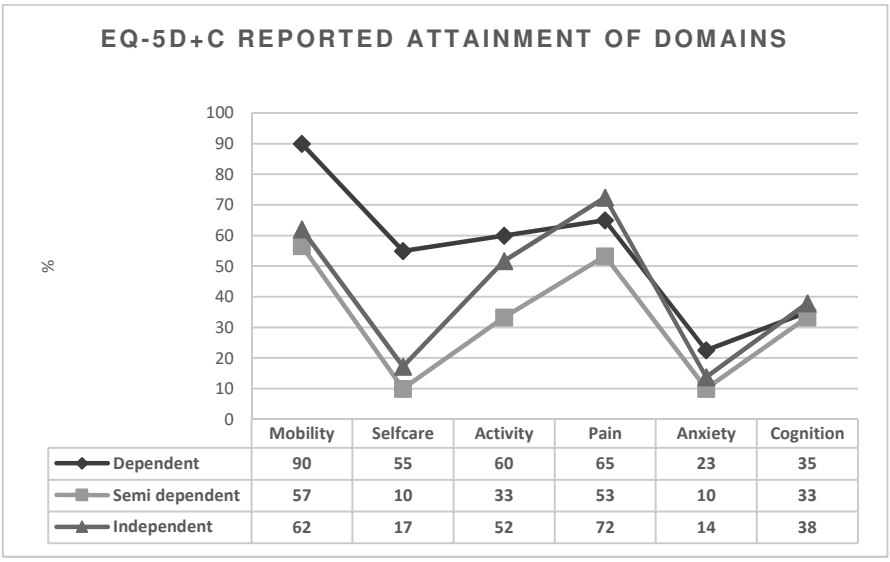


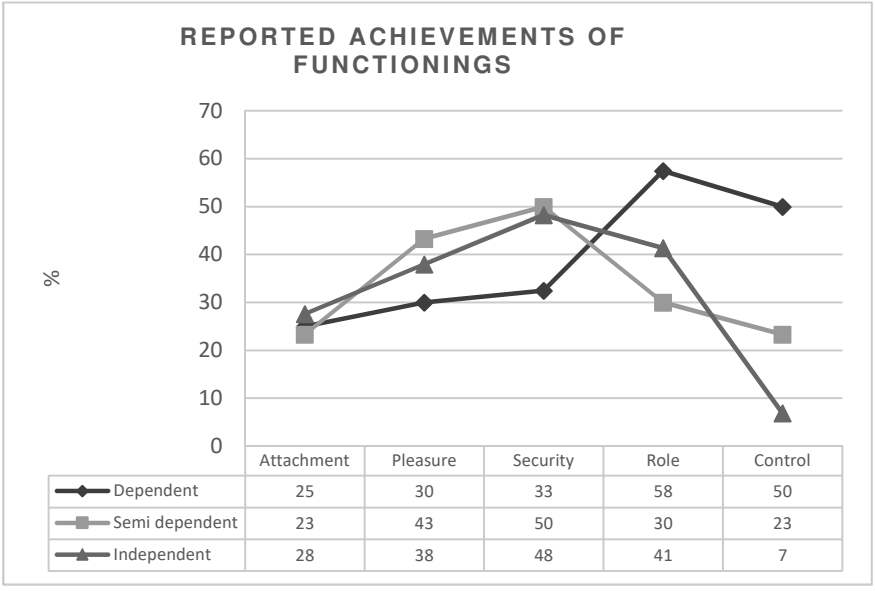
Fig 1: EQ-5D utility scores

When ranking the domains on specific reported problems, from high to low, it is evident from the results that the dependent group ranked the domains as follows: mobility; pain; daily activity; self-care; cognition and anxiety (Fig 2). The semi-dependent group ranked the reported problems across the domains as follows: mobility; pain; daily activity/ cognition selfcare/anxiety. Lastly, the independent group rated the reported problems in the domains as follows: mobility; pain; cognition; daily activity; self-care and anxiety. Notably the dependent elderly also reported the most problems in achieving positive outcomes across all domains investigated.



	Mobility	Selfcare	Activity	Pain	Anxiety	Cognition
Dependent	90	55	60	65	23	35
Semi dependent	57	10	33	53	10	33
Independent	62	17	52	72	14	38

Fig 2: EQ-5D+C reported attainment of domains for three subgroups of elderly



	Attachment	Pleasure	Security	Role	Control
Dependent	25	30	33	58	50
Semi dependent	23	43	50	30	23
Independent	28	38	48	41	7

Fig 3: Reported achievements of functionings

The results of the Currently Achieved Functionings questionnaire indicated that the dependent elderly group investigated in the study reported the most problems in achieving their functionings. The results of the currently achieved capabilities questionnaire are summarized in Fig 3. When ranking the problems experienced with their functionings, from high to low, the dependent group ranked their problems as follows: role; control; security/pleasure; attachment. The semi-dependent group ranked their problems in achieving functionings in the following order: security; pleasure; role and control /attachment. Lastly, the independent group ranked their problems as: security/ pleasure; role; attachment and control

Discussion

The results of the utility scores calculated from the EQ-5D+C questionnaire indicated that suffering from any of the five diseases, psychological disorders, heart disease, joint disorders, diabetes and hypertension, relegates the oldest old elderly to positions of suboptimal utility. This result corroborates previous studies indicating that diseases do play a significant role in determining QoL and might be of specific importance for the oldest old individuals. [15]

The finding also suggests that the five diseases will consign all the subgroups to potential disability. It is, however, important to note differences in utility score between the groups. Clearly it is

not only prevalent disease that determines functional status, but also other health and non-health factors. In line with this fact, the results indicate that mobility and pain were the major domains, across the three groups, resulting in most problems reported. Recurring problems with mobility and persistent pain can certainly influence the functional status of an individual with negative consequences. Additionally, the high prevalence of joint disorders in all three subgroups appears to be a relevant factor to recognise.[31] This result is also in line with previous studies indicating that musculoskeletal disorder has a significant negative impact on elderly physical as well as mental health.[32]

The dependent elderly reported the lowest utility score indicating they are struggling with disability. The dependent elderly also reported that they had the most problems in obtaining the mobility functioning. In part this may be attributable to the fact that they often had suffered a stroke, which has been indicated to have a high disabling impact.[31] A non-fatal stroke regularly causes disability such as mobility limitations.

Additionally, from the functionings results it is clear that the dependent elderly is the group struggling to achieve the role and control functionings. The fact that the dependent elderly suffer from a higher prevalence of heart disease, can be a possible explanation for the deficit in role achievement.[33] All these factors taken together might impact on the ability of the dependent group to be in control of their lives and to be self-sufficient.[34]

The semi-dependent and independent groups are possibly concerned about the status of the health and finances since both groups reported that security, which includes monetary concerns and health, are affected considerably. Furthermore, literature suggests that impairment in leisure activities is related to "lower levels of symptom management and less active coping behaviour".[35] The semi-dependent group however had the highest utility scores suggesting that the semi-dependent group is already in a transition phase of their health. Being semi-dependent might be the most comfortable place to be regarding health outcomes, since the reality of a decline in health is apparent to the semi-dependent group, although they can still perform certain tasks and remain in control of their lives. [36]

Importantly, contrary to other studies, the findings indicate that the independent elderly experience better functioning in the presence of chronic disease when compared to dependent elderly.[37] This result indicates that within the oldest old group there are subgroup differences, further strengthening the idea that wellbeing is an individualized concept with resource and disease interactions at various levels.

The major difference in sociodemographic resources between the groups was the fact that more than two people were living in the dependent elderly's household. We hypothesize that a possible mediating factor might be the fact that the dependent elderly need

constant assistance of a care worker. This can certainly diminish one's autonomy and the ability to be in control of one's life.[34]
Finally, all the subgroups rated anxiety and as the aspect which was least burdensome. The dependent group rated attachment as the functioning with which they had the least trouble achieving, while the semi-dependent and independent groups rated control as functioning with which they had the least trouble achieving. We hypothesize that this fact in itself can be a mediating factor and can be transformed into a resource. The autonomy factor of control and the absence of significant anxiety levels can empower the semi-dependent and independent elderly to experience less disability, when compared to the dependent elderly. [1] How the dependent elderly experience less trouble in achieving the attachment, pleasure and security functionings, is unclear. It is plausible that dependent elderly feel that, given the worse QoL and wellbeing experience, the achieved levels of attachment, pleasure and security remain acceptable, while deficits in control and a purpose in life are not acceptable.

The implications of the results suggests that although disease does affect QoL and wellbeing, the achievability of health domains and functionings, can enhance or impair the development of disability. The influence of a disease is not the same for all groups and should be considered in conjunction with other mediating factors to determine disability. Health and disability is a highly individualized concept, with disease profiles, available resources

and achieved health domains and functionings impacting on the ability of the oldest old to manage and cope with disability.

Assisting the elderly groups, based on dependency levels for instance, in achieving these resources could then allow for concepts like equity and self-efficacy to be embedded into elderly care programs. Achieved health or non-health factors, acting as resources, empowering each individual with various pathways to achieve personal QoL and wellbeing goals. This could possibly translate into a societal benefit in terms of health resource utilization and prevention of early disability.

This information must be relayed to the elderly patient so they can formulate informed and effective health care choices.[38] The results however do indicate that addressing deficits in health related issues such as mobility and pain experience remain a universal issues the oldest old face. Addressing these two critical aspects of daily life can have a positive impact on non-health related aspects that determine overall wellbeing.

Effective pain management and adequate mobility is certainly essential for the achievement of other health related and non-health related domains that determine QoL and wellbeing. As such, tailored programs aimed at preventing disease, causing mobility limitations, and effectively managing pain should be an important priority for health care services.

The study has a few limitations which should be mentioned. Firstly, the CAF questionnaire is a conceptual questionnaire and

was not yet validated for its present use. The pilot studies performed, however, confirmed the feasibility of the CAF questionnaire for use in our study. Secondly, although evidence supports the idea of using suboptimal utility attached to certain diseases to describe QoL, it is not a standard practice and must be interpreted with other factors as mentioned in the paper.[39] Finally, since this study was performed in the Northern part of the Netherlands and with a limited number of respondents future studies must include more respondents and include more Dutch provinces to further support the inferences made by this study. Amid these limitations, the strength of this study is substantial since important findings were corroborated whereas also new associations were found. A considerable and expanding body of evidence exist to support the results and findings of this study.

It is clear that when comparing elderly based on three dependency levels, the oldest old dependent elderly are a group at risk of experiencing considerable problems in health and wellbeing outcomes.

It is therefore important to understand how prevalent disease unique to a group, region or population interacts with the resources available and to protect against disability. Health, disability and resource utilization is however a very personal endeavour that translates into the ability or inability of people to manage and succeed on physical, emotional and social arenas.

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Chapter 7

General discussion

Aging with chronic disease - Perspective on HRQoL and wellbeing

It is widely recognized that there are common issues influencing elderly wellbeing and quality of life (QoL). Elderly populations all face disease trajectories and profiles that exert pressure on the achievement of wellbeing and QoL goals. Previous studies have indicated that disease and multi-morbidity is a probably of life for the oldest old, with the potential to cause significant disability. [1] Furthermore, it has been demonstrated that QoL deteriorates before disability ensues but also that adaptation to disability occurs eventually. [2] These observations lack an overarching theoretical model and thus may be difficult to comprehend. Understanding what the disability entails in terms of affected quality of life, life expectancy and limitations is of utmost importance.

It has been suggested that rather than just focusing on health related disability, oldest old policy should aim to assist the oldest old to adapt to their reduced QoL and wellbeing status.

Evidently, older olds prefer functional independence while younger olds prefer less morbidity. [3] To achieve the objectives of functional independence for the oldest olds and less morbidity for the younger olds, two distinctive approaches might be required that incorporates elderly subgroup variables. A shift from conventional disease management, towards guiding the oldest old

patient to a sustainable solution for wellbeing achievement. Interventions aimed at allowing the oldest old to adapt to a reduced QoL and wellbeing health states, aspire, and reach realistic capabilities and functionings. Importantly, the primary role of health care services will have to be reorganized to enhance oldest old personal choice and control over health care decisions, while still proving prove to be a cost-effective strategy By now, however, evidence indicates that a one size fits all approach to elderly health care and wellbeing is not feasible.The challenge, in the meantime is to maintain and sustain appropriate health care services, i.e, services should remain dependable, sustainable and cost-effective. Policy makers thus may have to make tough choices based on health care benefit and cost, with the obligation to incorporate elderly health perceptions and health care needs.

In this thesis, we formulated specific questions to investigate elderly health perceptions and preferences in occurrence of prevalent chronic disease. First, we investigated: How chronic disease and multi-morbidity will influence elderly disability trajectories. We applied a multi-state life table approach to elderly aged 65 and over in the Netherlands in 2007. Time spent with disease, has obvious QoL and and potential disability implications for the elderly individual. In concurrence with the latter, the allocation of health care resources is largely determined by prevalent disease and the effects of the disease on QoL. The results provide a valuable insight for clinicians and policy makers. Based on the results obtained, future interventions may be

designed such that disability across the life course is minimised. Prevention and care should be specific to sex and age, both for single diseases and multi-morbid conditions.

The life table results indicate that, from all the diseases investigated, osteoarthritis and CHD are the two diseases with the potential to cause significant disability in the female and male elderly population respectively. [4]

As multi-morbidity within the elderly population is common, our life table approach investigating multi-morbid disease profiles indicate that individuals with both diabetes and osteoarthritis, as a multi-morbid health state, can potentially be very disabling. Addditionally, the multi-morbid heath states including dementia and stroke seem especially impactful for the “oldest old” individuals, since it increases the percentage of time men and women will spent in a diseased state. This result may relate to the concept of surviving a non-fatal stroke, while suffering from dementia. [5, 6] This life course renders the oldest old individuals with very little autonomy, and would seem to designate the remaining life expectancy to be spend in an extremely disabled and care dependent state.

The results support the premise that osteoarthritis is a disease that should be a priority for prevention. It is a well-known fact that osteoarthritis will affect domains such as mobility, pain experience and even self-care. Implementation of a cost-effective prevention program aimed at the female and male population can have

significant positive QoL implications for the elderly. Just by preserving mobility in the elderly the positive knock-on effect on overall wellbeing can be significant. [7] In the male population, better management of CHD will improve survival for the population suffering from CHD. Men with CHD live longer, but may also spend more time in potential disability. Clearly preventing the development of CHD in the male population may be critical, rather than at a later stage management of CHD. The results indicate that managing CHD prolongs survivorship, but also burdens health care with managing long term CHD associated disability. [8]

Moreover, preventing multi-morbid health states that include diabetes and osteoarthritis is more complicated than managing a single disease. Thus preventing coincidence an subsequent multi-morbidity of this kind is essential. Reducing highly disabling multi-morbid health states can have a positive impact on the HRQoL and wellbeing of the elderly population, while reducing health care utilization. [9]

Realizing the effects of disease, on QoL and potential disability, we continued our investigation with a pilot study, performed in both the Netherlands as well as South Africa, to firstly determine the feasibility of two methods used to describe and value health states. The results indicate that the respondents preferred the visual analogue scale (VAS) method to the time trade off (TTO) method, due to the fact that the TTO technique was cognitively more demanding when compared to the VAS technique. The VAS

method requires health states, rated on a visual analogue scale, typically ranging from 0 (worst off) to 100 (full health). The TTO technique requires the respondents to value how much time in health state 111111 (full health) was equivalent to 10 years spent in a target state. Target states represent different levels of deterioration in QoL. Thus, a typical TTO valuation task would involve a hypothetical trade-off between length and quality of life.

The EQ5D+C, an extended version of the standard EQ-5D, and the Currently Achieved Functioning (CAF) questionnaire showed consistent results in terms of logical order of the health state valuations. The Currently Achieved Functioning questionnaire was developed to investigate the achieved functioning and not the functional aspirations or capabilities of the elderly respondents. The CAF questionnaire included the attachment, enjoyment, security, role, and control attributes, with five response categories possible.

The extended version (EQ-5D+C) of the standard EQ-5D included the “cognitive functioning” as an additional attribute. The standard EQ-5D classification system developed by the EuroQol Research Foundation (https://euroqol.org/) describes health related status according to five attributes: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each attribute has three levels: “no problems” (“1”), “some problems” (“2”), and “severe problems” (“3”).

Both questionnaires showed the same pattern, with better health states valued closer to one, while worse off health states were valued closer to zero. [10] The results of this study indicated that elderly individuals from different subgroups and even different parts of the world are able to describe and value, health related and achieved functioning included in the EQ-5D+C and CAF questionnaires.

After identifying a feasible method to perform the health state description and valuations, we then proceeded to investigate how elderly value hypothetical health states using both the EQ-5D+C and the CAF instrument.

Elderly individuals living in the Northern part of the Netherlands (Groningen, Veendam and Hoogeveen) were invited to participate in the study. Inclusion criteria were age 65-years and older fulfilling one of the following living arrangements, to investigate whether there will be differences between subgroups: Living independently; (still looking after themselves); living semi-dependently with moderate care and living in a nursing home requiring regular care. The total sample of the study comprises 99 respondents, 29 living independently, still looking after themselves, 30 living semi-dependently with moderate care and 40 living in a nursing home requiring consistent care.

The valuations of both the EQ-5D+C and CAF questionnaires show that the three subgroups valued the same health states below the average scores of the subgroups. Conceivably, the

health states below the average scores of the subgroups are deemed undesirable or unacceptable due to the low values placed on the health states by all three subgroups of elderly. Interestingly, it became evident that overall the average values across the health states of the achieved functioning health states are higher than the health states of the EQ-5D+C questionnaire. Qualitative research relating to how elderly value health states indicates that elderly already consider the consequences of deficits in health on non-health factors, during the valuation process. [11]

This suggest that preserving health related domains as defined by the EQ-5D+C (mobility, self-care, usual activities, pain/discomfort, anxiety/depression and cognition) may be a good approach to positively influence non-health aspects (social interaction and attachments to family and friend, control over one's life and a sense of purpose) thus improving overall wellbeing. Although this is a subjective exercise performed by the oldest old, previous research has indicated that a health domain like mobility may have an impact on both health and non-health factors. Deficits in mobility are associated with worse psychological health, higher incidence of depression, lower purpose in life, less resilience and less social support. [12] This brought us to the question of how elderly describe their own health using the EQ-5D+C and the CAF questionnaire.

The results from the EQ5D+C utility instrument indicated that the semi-dependent and independent groups with joint disorder reported the lowest utility scores of 0.80 and 0.57 respectively. In the dependent group, however, psychological disorder resulted in the lowest utility score of 0.11. This result was because only two respondents reported psychological disorder with apparently very low scores. Excluding this result would move heart disease into the lowest position for the dependent elderly, with an utility score of 0,49. Overall, the respective average utility scores calculated for the dependent, semi-dependent and independent subgroups were 0.56, 0.84 and 0.69. This finding is in line with previous research indicating that musculoskeletal disease and cardiovascular disease do play a significant role in determining QoL, and might be of particular importance for the oldest old individuals. [13]

The loss of mobility and pain were the major domains, across the three groups, resulting in most problems reported. Sustained problems with mobility and persistent pain can undoubtedly influence the functional status of an individual negatively. [12] Additionally, the results from the CAF questionnaire show that the dependent elderly are the group not achieving the role and control functionings. The dependent group is the high-risk group reporting more problems regarding HRQoL and wellbeing goals. The fact that the dependent elderly need continuous succour of a care worker, spouse or family member can certainly moderate one's autonomy and the ability to be in control of one's life. [14] The

autonomy factor of control and the absence of significant anxiety levels may empower the semi-dependent and independent elderly to experience less disability, when compared to the dependent elderly. [15, 16]

The results from this study suggest that preservation of mobility must be a priority for health professionals, patients and caregivers. Mobility is a gateway to more independence, social interaction and self-preservation. [17, 18] Additionally, preventing and managing pain in the oldest old population can also contribute to better wellbeing outcomes. Clearly, engaging elderly to actively preserve HRQoL domains is essential to regain a sense of purpose and control and to enhance wellbeing. [19, 20]

Implications

Even though a shift from current cure practices to implementation of a multi-dimensional and personalized care system for the elderly is warranted, [21] it is evident that older individuals do require interventions that will prevent specific disease and preserve important functional abilities. Reducing the prevalence of CHD for men and osteoarthritis for women, the multi-morbid combination of diabetes and osteoarthritis, and the multi-morbid combination of stoke and dementia for the oldest old population would likely increase QoL while reducing health care utilization. To achieve this goal may seem challenging but evidence shows that simple and regular physical activity has the potential to either lessen or

prevent physiological and cognitive decline with ageing. [22] [23] In fact, while aging of the musculoskeletal system including muscles, skeletons and joints appears to develop prematurely in women, aging of blood vessels (arteriosclerosis) that causes vascular damage tends to develops prematurely in men. Although both aging courses are unfavourable to survival, aging of blood vessels can lead to fatal events, such as cerebral haemorrhage and infarction. In contrast, although aging of the musculoskeletal system might lead to functional decline, it is not immediately fatal. These phenomena suggest that although overall women live longer, they also have a longer unhealthy lifespan compared with men. [24] Realising that 'exercise may be a potent medicine' is therefore important to prevent the aging of blood vessels or arteriosclerosis in men, while preventing deterioration of the musculoskeletal system in women.

There is robust evidence to confirm that focussing on maintaining functional abilities will have a positive impact on non-health aspects and should be prioritized. [25, 26] While primary interventions are more effective when implemented early in the elderly life course, secondary prevention strategies can be implemented to enhance or maintain elderly function that already experience baseline dysfunction. [23] It is however clear that the oldest old do prefer function preservation. Maintaining mobility and preventing and managing pain must be a priority. Mobility is a critical utility that allows the elderly the opportunity to engage life in a

meaningful way by being more independent, socially active and self-reliant.

Although we focussed on functionings rather than on capabilities, applying the principals of the capability approach to help elderly identify what is relevant to their wellbeing and what is realistically achievable, can still be a valuable tool for medical and social care providers. This can only be achieved through active engagement and attention to the patient's distinctive desires specific for each patient engagement phase. [27] It is important to realize that these interventions should be specifically tailored for the various demographic settings, socio-economic circumstances and dependency levels of the oldest old. [28] Therefore, it is imperative to involve the oldest old in health state valuations and descriptions to guarantee that elderly wellbeing needs are addressed. Focused goal setting and realistic achievable plans provide elderly with the adaptational skills to better manage disease affected health states. [29] Ultimately, this may lead to less disability among the elderly population, with fewer resources spent on disease management, while still preserving critical functions important to the oldest old individuals to life a live worth living.

Future research

It may be essential to incorporate the main results of this study to test the relevance of the outcomes. First, future research should focus on a prevention strategy aimed at addressing the morbidity

caused by prevalent disease, within elderly subgroups. The intervention strategy should consist of primary interventions, such as a physical activity program, as well as secondary interventions aimed at addressing older patients already suffering from prevalent disease. The outcomes of the intervention can possibly provide conclusive evidence for the benefit of a tailored disease prevention program for elderly.

Secondly, an intervention aimed at preservation of mobility and preventing and managing pain in the oldest old can be initialized, to test the effect on non-health aspects such as a sense of purpose, control and attachments.

Critically, future research should stimulate patient engagement, allowing elderly to become participant in their own health with guidance from medical and social domains. The ultimate goal of the research should be to empower elderly to adapt and manage disease affected health states with positive implications for HRQoL and wellbeing.

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Summary

Within the elderly population subgroups facing specific disease trajectories, may have different preferences with regard to aspects of HRQoL and care concepts. [1] Accordingly, to enable relevant health descriptions and valuations of the phases of aging the elderly population must be actively engaged. However, in the absence of a single suitable instrument to evaluate elderly wellbeing and health related quality of life (HRQoL), we proposed to answer the following questions:

Review of literature: Elderly morbidity, quality of life (QoL) and capabilities

In *chapter 2* we review important concepts and literature relating to the fact that health care preferences might not be the same for all the subgroups of elderly, and therefore should be recognized as such when developing treatment and care options for future elderly populations.[2] As populations are ageing extensive deliberation has emerged about the implications for sustainability of health care services. [3, 4] Chronic diseases or disorders will invariably have an effect on elderly functioning, QoL and health resource utilization. However, very little information is available to validate the health care choices of healthy elderly, compared to the choices of frail elderly. [5]

In lack of a comprehensive conception of age and phase of life applicable outcomes of health care, we posed the next question: **How will chronic disease and multi-morbidity influence elderly disability projections?** In *chapter 3*, we investigated the

effect of single and multi-morbid disease using a multi-state life table approach. The life tables were applied to data from 2007 and time spent with disease projections made, within 5-year age groups, up to the 85+ age group.

Over the life course elderly may contract multiple chronic conditions such as diabetes, CHD, osteoarthritis, CHF, stroke or dementia, and as a result will spend progressively more of the remaining life years with disease. Indeed the morbidity associated with diabetes, CHD, osteoarthritis, CHF, stroke and dementia increases from one age group to the next. The elderly with different cancers and COPD, however, do not show such an increasing trend in morbidity. Possibly cancer and COPD more often are associated with shorter survival and thus less burden through morbidity when compared to diabetes, CHD, osteoarthritis, CHF, stroke and dementia. This clearly indicates important differences in disease and disability occur over the life course, which need to be considered in planning for health care and in developing interventions. In addition, for women osteoarthritis has the largest impact on time spent with disease, whereas for men CHD will have the largest impact on time spent with disease.

The multi-morbidity life table results indicate that elderly men and women with more than one disease should be considered as a separate group with unique health related concerns. Both men and women suffering from diabetes and osteoarthritis would

spend the most time in a disabled state. The multi-morbid heath states including dementia and stroke seem especially impactful for the oldest old age groups 80-84 and the 85+ individuals, since it increases the percentage of time men and women will spent in a diseased and care dependent state. Pro-active primary and secondary disease prevention strategies specifically designed for the elderly population seem warranted. Based on the effects of disease on the elderly life course, we explored the following question:

How do the elderly experience scoring and valuing health states from a preference based (utility) instrument: the EQ-5D+C compared to a capability instrument *(functionings)* like the Currently Achieved Functionings (CAF)?

In *chapter 4,* we discussed the results of a pilot study performed in both the Netherlands as well as South Africa to firstly to determine the feasibility of two methods used to describe and value health states. The first method evaluated used a visual analogue scale (VAS), the second was the Time Trade Off method (TTO). Secondly, we aimed to study the feasibility of the EQ-5D+C and the Currently Achieved Functionings (CAF) questionnaire, to provide comprehensive insight, and assess whether relevant complimentary information may be obtained on quality of life and health state valuations for use in a study among elderly in the Dutch population.

The South African sample comprised 30 respondents living independently, while the Dutch sample comprised 30 respondents divided into three groups of ten according to the respondent's living arrangements. Ten were living independently, ten were living semi-independently, and the last group were living in an elderly care centre.

Previous studies have shown that TTO techniques place a great cognitive burden on respondents, since they require a high degree of abstract reasoning. [6] Taking this into consideration, the decision was made to use a simplified version of the TTO exercise. [7] A typical TTO valuation task would involve a hypothetical trade-off between length and quality of life. In line with previous studies, our simplified TTO proved to be too complicated for the majority of respondents, and we subsequently decided to proceed with the VAS method. In our study, the visual analogue scale method requires ten health states, ten from the CAF and ten from the EQ-5D+C, each rated on a scale, typically ranging from 0 (worst off) to 100 (full health). It was made clear that the value of 100 on the VAS would be considered to be the best possible value attainable and that the 0 value would be considered equal to death. The respondents were also instructed to consider the whole scale and not just the marked intervals. [8] Care was taken to instruct the individuals not to consider their own health when valuing the health states. Instead they had to view the valuation procedure as a task regarding a hypothetical state.

The results indicated that the respondents preferred the VAS method to the TTO method. Furthermore, both the South African and Dutch elderly performed the health state descriptions and valuations with ease using either questionnaire. Both the EQ-5D+C and CAF were able to extract relevant health descriptions and health state valuations, while retaining the ability to distinguish between elderly subgroups. Based on the results of this pilot study we decided to include both the EQ-5D+C questionnaire and the CAF questionnaire in the health sate descriptions and valuation exercise, since the questionnaires would capture elderly HRQoL and functionings. We then formulated and investigated the following question: **How do the elderly value *hypothetical health states* using both the EQ-5D+C and the CAF instrument?**

In *chapter 5*, we investigated the valuation performed by elderly individuals living in the Northern part of the Netherlands (Groningen, Veendam and Hoogeveen). Inclusion criteria were aged 65-years and older, living in one of the following living arrangements: living independently; still looking after themselves; living semi-dependently with moderate care, and living in a nursing home requiring consistent care. The total sample of the study comprised 99 respondents, 29 living independently, still looking after themselves, 30 living semi-dependently with moderate care and 40 living in a nursing home requiring consistent care.

The standard EQ-5D classification system developed by the EuroQol Research Foundation (https://euroqol.org/) describes health status according to five attributes: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each attribute has three levels: “no problems” (“1”), “some problems” (“2”), and “severe problems” (“3”). Health state descriptions are constructed by choosing one level for each attribute (e.g., the best health state is represented by 11111). The non-standard EQ-5D+C is similar to the EQ-5D, but with a 3-level cognition attribute added.

The Currently Achieved Functioning questionnaire was developed to investigate the achieved functionings, and not the functional aspirations or capabilities of the elderly respondents. The CAF questionnaire included the attachment, enjoyment, security, role, and control attributes, with five possible response categories. Inspiration for the development of the CAF came from the work performed by Grewal and colleagues. [9]

The dependent elderly valued the majority of the health states the highest of the three groups. The dependent elderly still place a higher value on worse off health states, when compared to the other two groups. The valuations of the EQ-5D+C and CAF questionnaire indicate that all three subgroups ranked the same health states below the average scores of the subgroups. Additionally, the average values across the health states of the CAF health states are valued higher than the health states of the EQ-5D+C questionnaire. Subjectively this relates to the idea that

elderly do value deficits in health related factors as more important than deficits in non-health related factors. This relates to the concept of preserving and maintaining everyday abilities, which may be more relevant to resilience in advanced age. [10] Our results are therefore relevant since it reiterates the effects of subjective health domains on non- health aspects, as evaluated by the oldest old. This seems to indicate that preserving health domains as defined by the EQ-5D+C (mobility, self-care, usual activities, pain/discomfort, anxiety/depression and cognition) may be a good method to positively influence non-health aspects that determine overall wellbeing. This led to the following question: **How do elderly describe their *own health* using the EQ-5D+C and the CAF questionnaire?**

In *chapter 6*, the EQ-5D+C and CAF questionnaires were used during structured interviews to retrieve the data. The proportion of respondents reporting some problems and extreme problems were calculated, within each subgroup, in each of the EQ-5D+C domains. The EQ-5D+C/utility scores for each subgroup, type of disease (hypertension, heart disease, diabetes, psychological disorder, joint disorder) were calculated.

The CAF questionnaire is theoretically rooted in the capability approach. The currently achieved functionings questionnaire used the five attributes (Attachment, Enjoyment, Security, Role and Control*)* to investigate elderly functionings. Problems reported as limitations in utility and functionings were regarded as

respondent's inability to perform or achieve relevant QoL and wellbeing levels.

The results from the CAF questionnaire show that the dependent elderly are the group not achieving the role and control functionings. This suggests that the dependent elderly struggle to find a sense of purpose(role) in their lives and also feel like they are not in control of important decisions in their lives. The semi-dependent and independent groups rated control as functioning which they had the least trouble achieving. Although the semi-dependent and independent groups reported significant under achievement of the security functioning and pleasure functioning, being semi-dependent might be the most comfortable place to be regarding health outcomes. The reality of a decline in functioning is apparent to the semi-dependent group, although they can still perform certain tasks and remain in control of their lives. [11]

The results indicate that loss of mobility and pain were the major domains, across the three groups resulting in most problems reported. In addition, the results from the EQ5D+C utility instrument indicated that the semi-dependent and independent groups with joint disorder reported the lowest utility scores of 0.80 and 0.57 respectively. The dependent elderly with heart disease reported the lowest utility score with 0.49. This result is in line with preceding research demonstrating that musculoskeletal disease and cardiovascular disease do play a significant role in

determining QoL and might be consequential for the oldest old individuals. [12]

In *chapter 7*, we discussed the findings reported in this thesis. We formulated and answered specific question related to disease trajectories and HRQoL and wellbeing preferences of elderly living in the Netherlands. We advocated that elderly do require interventions that will prevent prevalent disease and preserve important functional abilities, like mobility. We, however, stress that simply addressing disease is not sufficient. Guidance from care-providers, medical and social domains will have a central role here to help elderly identify what is relevant to their wellbeing, and what is realistically achievable. This can only be achieved through active engagement and attention for the patient's distinctive desires of each patient engagement phase. [13]

Binnen ouderen kunnen subgroepen met specifieke ziektetrajecten verschillende voorkeuren hebben met betrekking tot aspecten van gezondheidsgerelateerde kwaliteit van leven(KvL) en vormen van zorg. [1] Om beschrijvingen van relevante gezondheidstoestanden en waarderingen van de fases van veroudering mogelijk te maken, is het van belang de oudere bevolking hierbij actief te betrekken. Omdat er tot voorkort geen enkel geschikt instrument was om het welzijn van ouderen en de gezondheid gerelateerde KvL te evalueren, hebben we het huidige onderzoek uitgevoerd aan de hand van een aantal vragen:

Literatuuronderzoek: morbiditeit, kwaliteit van leven (KvL) en capaciteiten in de oudere populatie.

In *hoofdstuk 2* bespreken we belangrijke concepten en literatuur met betrekking tot het feit dat de voorkeuren van de gezondheidszorg mogelijk niet dezelfde zijn voor alle subgroepen van ouderen, die derhalve zouden moeten worden verdisconteerd bij het ontwikkelen van behandelings- en zorgopties voor toekomstige ouderenpopulaties. [2] Veroudering van de bevolking heeft geleid tot uitgebreide beraadslaging over de implicaties voor de duurzaamheid van zorgdiensten. [3,4] Chronische ziekten of aandoeningen zullen een effect blijven hebben op het functioneren van ouderen, KvL en gebruik van zorg. Er is echter weinig informatie beschikbaar om de gezondheidskeuzes van gezonde ouderen te valideren, in vergelijking met de keuzes van kwetsbare ouderen. [5]

Bij gebrek aan een qua leeftijd en levensfase breed toepasbaar instrument om uitkomsten van de gezondheidszorg te meten, stelden we de volgende vraag: **Hoe zullen chronische ziekten en multimorbiditeit de prognoses voor ouderen met een beperking beïnvloeden?** *In hoofdstuk 3* onderzochten we het effect van een enkele en multi-morbide ziekte met behulp van een levenstabellen-benadering. De levenstabellen werden toegepast op gegevens uit 2007. Vervolgens werd de tijd doorgebracht met ziekte geraamd, binnen leeftijdsgroepen van 5 jaar, tot de leeftijdscategorie van 85+.

Gedurende de levensloop kunnen ouderen onder andere diabetes, CHD, osteoartritis, CHF, een beroerte of dementie ontwikkelen, en zullen als gevolg daarvan steeds meer van de resterende levensjaren met ziekte doorbrengen. De morbiditeit geassocieerd met diabetes, CHD, osteoartritis, CHF, beroerte en dementie neemt inderdaad toe met de leeftijd(sgroep). Ouderen met verschillende vormen van kanker en COPD vertonen echter niet zo'n stijgende trend in morbiditeit. Mogelijk worden kanker en COPD vaker in verband gebracht met kortere overleving, en dus minder morbiditeit in vergelijking met diabetes, CHD, osteoartritis, CHF, een beroerte en dementie. Dit geeft duidelijk aan dat er belangrijke verschillen in ziekte en invaliditeit optreden gedurende de levensloop, waarmee rekening dient te worden gehouden bij het plannen van de gezondheidszorg en bij het ontwikkelen van interventies. Bovendien heeft osteoartritis voor vrouwen de grootste invloed op de tijd die met ziekte wordt doorgebracht,

terwijl CHD voor mannen de grootste invloed heeftl hebben op de tijd die met ziekte wordt doorgebracht.

De reslutaten uit de multilorbiditeitstabel wijzen erop dat oudere mannen en vrouwen met meer dan één ziekte moeten worden beschouwd als een afzonderlijke groep met unieke gezondheid gerelateerde problemen. Zowel mannen als vrouwen met diabetes en artrose zouden de meeste tijd met een beperking doorbrengen. De meervoudig morbide gesondheids-toestanden, waaronder dementie en beroerte, lijken vooral van invloed te zijn op de oudste leeftijdscategorieën van 80 tot 84 jaar, en 85jaar en ouder. Dit komt doordat de tijd die mannen en vrouwen in een zieke en zorgafhankelijke staat zullen doorbrengen toeneemnt. Pro-actieve primaire en secundaire ziektepreventie strategieën specifiek ontworpen voor de oudere populatie lijken gerechtvaardigd. Gezien de effecten van ziekte op de levensloop van ouderen, onderzochten we de volgende vraag: **Hoe ervaren en scoren ouderen gezondheidstoestanden die beschreven zijn met een op preferenties gebaseerd (hulpmiddel) instrument: de EQ-5D + C in vergelijking met een capaciteitsinstrument (functionering) zoals de Current Achieved Functionings (CAF)?** In *hoofdstuk 4* bespraken we de resultaten van een pilotstudie uitgevoerd in zowel Nederland als Zuid-Afrika om eerst de haalbaarheid te bepalen van twee methoden die worden gebruikt om gezondheidstoestanden te beschrijven en te waarderen. De eerste methode was een visueel analoge schaal (VAS) en de tweede was een Time Trade Off-

methode (TTO). Ten tweede hebben we de haalbaarheid van de EQ-5D + C en de Current Achieved Functionations (CAF) vragenlijst onderzocht om uitgebreid inzicht te verkrijgen en te beoordelen of relevante aanvullende informatie over de kwaliteit van levens- en gezondheidstoestandwaarderingen voor gebruik in een studie onder Nederlandse ouderen.

De Zuid-Afrikaanse steekproef bestond uit 30 onafhankelijke respondenten, terwijl de Nederlandse steekproef bestond uit 30 respondenten verdeeld in drie groepen van tien volgens de woonsituatie van de respondent. Tien woonden zelfstandig, tien leefden semi-onafhankelijk en de laatste groep woonde in een instellingvoor ouderenzorg.

Eerdere studies hebben aangetoond dat TTO-technieken een grote cognitieve belasting vormen voor respondenten, omdat ze een hoge mate van abstract redeneren vereisen. [6] Hiermee rekening houdend, werd besloten om een vereenvoudigde versie van de TTO- e gebruiken. [7] In een typische TTO-staak wordt een afweging gemaakt tussen lengte en kwaliteit van leven. In overeenstemming met eerdere studies bleek zelfs onze vereenvoudigde TTO opnieuw te gecompliceerd voor de meerderheid van de respondenten, en hebben we deze vervolgens weggelaten uit de Nederlandse steekproef.

In onze studie vereist de methode voor visuele analoge een schaal bestaande uit tien voor zowel de CAF als de EQ-5D+C. De gezondheidstoestanden geclassificeerd van 0 (slechtste) tot

100 (volledige gezondheid). Er werd duidelijk gemaakt dat de waarde van 100 op de VAS zou worden beschouwd als de best haalbare waarde en dat de 0-waarde gelijk zou zijn aan de dood. De respondenten kregen ook de opdracht om de hele schaal te beschouwen en niet alleen de gemarkeerde intervallen. [8] Aan de respondenten werd gevraagd hun eigen gezondheid niet in overweging te nemen bij het waarderen van de beschreven gezondheidstoestand. Het ging dus om het waarderen van een hypothetische toestand. Zowel de Zuid-Afrikaanse als de Nederlandse ouderen hebben de beschrijvingen van de verschillende gezondheidstoestanden en -waarderingen gemakkelijk kunnen uitvoeren met behulp van een vragenlijst. Zowel de EQ-5D + C als de CAF bleken geschikt om gezondheidstoestanden te beschrijven en waarderen. Met beide lijsten was het tevens mogelijk onderscheid te maken tussen subgroepen van ouderen.

Op basis van de resultaten van deze pilotstudie hebben we besloten om zowel de EQ-5D + C-vragenlijst als de CAF-vragenlijst op te nemen voor de beschrijvingen en waarderingen van de gezondheidstoestanden, aangezien de vragenlijsten ouderen-GKvL en functies zouden vastleggen. Vervolgens hebben we de volgende vraag geformuleerd en onderzocht: **Hoe waarderen ouderen hypothetische gezondheidstoestanden met behulp van zowel de EQ-5D + C als het CAF-instrument?** In *hoofdstuk 5* onderzochten we de waarderingen van ouderen in het noorden van Nederland (Groningen, Veendam en

Hoogeveen). Inclusiecriteria waren 65 jaar en ouder en woonachtig in een van de volgende omstandigheden: zelfstandig wonen; nog steeds op zichzelf letten; semi-afhankelijk wonen met enige ondersteuning, en wonen in een zorginstelling afhankelijk van professionele hulp. De totale studie groep bestond uit 99 respondenten, 29 zelfstandig wonende, 30 semi-afhankelijk met enige ondersteuning, en 40 wonend in een zorginstelling.

Het standaard EQ-5D classificatiesysteem beschrijft de gezondheidsstatus volgens vijf domeinen: mobiliteit, zelfzorg, dagelijkse activiteiten, pijn / ongemak en angst / depressie. Elk kenmerk heeft drie niveaus: "geen problemen" ("1"), "enigeproblemen" ("2") en "ernstige problemen" ("3"). Beschrijvingen van gezondheidstoestanden worden geconstrueerd door voor elk kenmerk één niveau te kiezen (bijv. De beste gezondheidstoestand wordt omschreven met het profiel 11111). De de EQ-5D kan worden aangevuld met een extra cognitie domein: de EQ-5D + C.

De Current Actived Functioning-vragenlijst is ontwikkeld om de bereikte functies te onderzoeken, en niet de functionele ambities of vermogens van de oudere respondenten. De CAF-vragenlijst bevat de attributen voor bijlagen, plezier, veiligheid, rol en controle, met vijf mogelijke antwoordcategorieën. Inspiratie voor de ontwikkeling van het CAF kwam van het werk van Grewal en collega's. [9] De afhankelijke ouderen waardeerden de meerderheid van de gezondheidstoestanden het hoogst van de drie groepen.

De afhankelijke ouderen plaatsen nog steeds een hogere waarde op slechter wordende gezondheidstoestanden, vergeleken met de andere twee groepen.

De waarderingen die werden gegenereerd op basis van de EQ-5D + C en CAF geven aan dat alle drie de subgroepen dezelfde toestanden rangschikten onder de gemiddelde scores van de subgroepen. Bovendien worden de gemiddelde waarden in de gezondheidstoestanden van de CAF hoger gewaardeerd dan de gezondheidstoestanden van de EQ-5D + C-vragenlijst. In de beleving van de onderzochte ouderen zijn beperkingen ten aanzien van gezondheidsgerelateerde factoren belangrijker dan beperkingen in niet-gezondheidsgerelateerde factoren. Dit heeft betrekking op het concept van het behouden van alledaagse capaciteiten, die mogelijk relevanter zijn voor veerkracht op latere leeftijd. [10] Onze resultaten zijn daarom relevant omdat het de effecten van subjectieve gezondheidsdomeinen op niet-gezondheidsaspecten onderschrijft, voor de oudste ouderen. Dit kan erop duiden dat het behoud van gezondheidsdomeinen zoals gedefinieerd door de EQ-5D + C (mobiliteit, zelfzorg, gebruikelijke activiteiten, pijn / ongemak, angst / depressie en cognitie) een goede methode kan zijn om niet-gezondheidsaspecten positief te beïnvloeden en het algemene welzijn.

Dit bracht ons bij het volgende vraag: **Hoe beschrijven ouderen hun eigen gezondheid met behulp van de EQ-5D + C en de CAF-vragenlijst?** In *hoofdstuk 6* werden ande hand van de EQ-

5D + C en CAF gestructureerde interviews gehouden. Het percentage respondenten dat enkele problemen en extreme problemen meldde, werd binnen elke subgroep berekend voor elk van de EQ-5D + C-domeinen. Daarnaast werden utiliteitsscores berekend, en voor verschillende subgroepen (type ziekte (hypertensie, hartziekte, diabetes, psychische stoornis, gewrichtsaandoening) gepresenteerd. De CAF-vragenlijst is theoretisch gebaseerd op de capability-benadering. De huidige functioningsvragenlijst gebruikte de vijf attributen (Attachment, Enjoyment, Security, Role and Control) om oudere functies te onderzoeken. Problemen die werden gemeld als beperkingen in bruikbaarheid en functioneren werden beschouwd als het onvermogen van de respondent om relevante QoL- en welzijnsniveaus uit te voeren of te bereiken.

De resultaten van de CAF-vragenlijst laten zien dat afhankelijke ouderen de groep zijn die de rol- en controlefuncties niet behaalt. De semi-afhankelijke en onafhankelijke groepen gaven aan dat controle de functie was waarmee ze het minst problemen hadden. Hoewel de semi-afhankelijke en onafhankelijke ouderen rapporteerden significant lager te functioneren op terrein van veilig voelen en plezier hebben, kan semi-afhankelijk zijn de meest comfortabele plaats zijn met betrekking tot gezondheidsresultaten. Een achteruitgang in functioneren is duidelijk waarneembaar in de semi-afhankelijke groep, hoewel deze ouderen nog steeds bepaalde taken kunnen uitvoeren en de controle over hun leven kunnen behouden. [11] De resultaten geven

aan dat verlies van mobiliteit en pijn de belangrijkste domeinen waren. In alle drie groepen werden hier de meeste problemen gerapporteerd. Bovendien gaven de resultaten van deEQ-5D aan dat de semi-afhankelijke en onafhankelijke groepen met een gewrichtsaandoening de laagste utiliteits scores voor van respectievelijk 0,80 en 0,57 rapporteerden. De afhankelijke ouderen met een hartziekte rapporteerden de laagste utiliteits score (0,49). Dit resultaat ligt in de lijn van eerder onderzoek waaruit blijkt dat aandoeningen van het bewegingsapparaat en hart- en vaatziekten een belangrijke rol spelen voor KvL. [12]

In *hoofdstuk 7* bespraken we de bevindingen gerapporteerd in dit proefschrift. We formuleren en beantwoorden specifieke vragen met betrekking tot ziektetrajecten en HRQoL en welzijnsvoorkeuren van ouderen die in Nederland wonen. We pleitten ervoor dat ouderen interventies nodig hebben die veel voorkomende ziekten voorkomen, en die zich richten op het behouden van belangrijke functies, zoals mobiliteit. We benadrukken dat het simpelweg aanpakken van een ziekte niet voldoende is. Begeleiding door zorgverleners, zowel uit het medische als uit het sociale domein zal hier een centrale rol in kunnen spelen om ouderen te helpen identificeren wat relevant is voor hun welzijn, en wat realistisch haalbaar is. Dit kan alleen worden bereikt door actieve betrokkenheid en aandacht voor de specifieke wensen van de patiënt die specifiek zijn voor elke patiëntbetrokkenheidsfase. [13]

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* BMC health services research: Published Ja n 2018. Relative contribution of various chronic diseases and multi-morbidity to potential disability among Dutch elderly.

* BMC geriatrics: Published Jan 2018: Functional health state description and valuation by people aged 65 and over: a pilot study.

* African journal of health professions education: Published Oct 2016. An inferential comparison between the capabilities and achievements of 1st-year medical and nursing students at the University of the Free State, Bloemfontein, South Africa.

* South African Medical Journal: Published Feb 2016. A cohort study of elderly people in Bloemfontein, South Africa, to determine health-related quality of life and functional abilities.

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* Human development and capability association conference, 2017; Cape Town, South Africa. Presentation: An integrative well-being model for the oldest old: The role of adaptation, capabilities and resources.

* ISOQOL conference, 20 11; Denver USA. Poster: Elderly Capabilities and Quality of Life in Prevention and Care of Disease: First Results.

Appendices

Appendix A

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Universitair Medisch Centrum Groningen

Medisch Ethische Toetsingscommissie

Telefoon (050) 361 4204
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Aan
Dr. K.M. Vermeulen
Epidemiologie **FA 40**

Bijlage(n)
Kenmerk M11.098466

Datum 4 maart 2011
Onderwerp METc 2011/041
Titel **Waardering van gezondheidstoestanden en kwaliteit van leven onder senioren: een pilot studie.**

De Medisch Ethische Toetsingscommissie van het Universitair Medisch Centrum Groningen (METc UMCG) heeft het bovengenoemde onderzoek besproken in haar vergadering van 3 maart 2011.

De METc UMCG is van mening dat bovengenoemd onderzoek geen medisch wetenschappelijk onderzoek met mensen is, zoals bedoeld in de Wet medisch-wetenschappelijk onderzoek met mensen (WMO).
WMO.

De METc UMCG besluit zodoende dat u geen positief WMO-oordeel behoeft, alvorens u met bovengenoemd onderzoek mag aanvangen.

Met vriendelijke groet,
namens de Medisch Ethische Toetsingscommissie,

b/a

prof. dr. W.A. Kamps
voorzitter

drs. J. Davids
ambtelijk secretaris

umcg

Appendix B

Grewal et.al description of attributes

Attribute	Descriptions
Attachment	Feelings of love, affection, companionship and friendship from your partner, family, friends and pets
Enjoyment	Participation in personal and group activities that is a source of pleasure and joy
Security	Feeling safe and secure, not feeling helpless when you consider factors like your finances and your health
Role	Having a purpose that provides you with a sense of value
Control	You feel independent and you make your own decisions

Appendix C

Choose one option that best describes you.

a) Attachment:
Feelings of love, affection, companionship and friendship from your partner, family, friends and pets

I have all the affection, love and companionship that I want
I have a lot of the affection, love and companionship that I want
I have some of the affection, love and companionship that I want
I have a little of the affection, love and companionship that I want
I have none of the affection, love and companionship that I want

b) Enjoyment:
Participation in personal and group activities that is a source of pleasure and joy

I have all the pleasure and enjoyment that I want
I have a lot of the pleasure and enjoyment that I want
I have some of the pleasure and enjoyment that I want
I have a little of the pleasure and enjoyment that I want
I have none of the pleasure and enjoyment that I want

c) Security:
Feeling safe and secure, not feeling helpless when you considering factors like your finances and your health

I feel very safe and secure when I think about the future
I feel safe and secure when I think about the future
I feel fairly safe and secure when I think about the future
I feel unsafe and insecure when I think about the future
I feel very unsafe and very insecure about the future

d) Role:
Having a purpose that provides you with a sense of value
I do all the things that provides me with a sense of purpose
I do a lot of the things that provides me with a sense of purpose
I do some of the things that provides me with a sense of purpose
I do a little of the things that provides me with a sense of purpose
I do none of the things that provides me with a sense of purpose

e) Control:

You feel independent and you make your own decisions

I make all of my own decisions and can be independent
I make a lot of my own decisions and can be independent
I make some of my decisions and can be fairly independent
I make a little of my own decisions and can be a little independent
I make none of my own decisions and can't be independent

Appendix D

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility

I have no problems in walking about □
I have some problems in walking about □
I am confined to bed □

Self-Care

I have no problems with self-care □
I have some problems washing or dressing myself □
I am unable to wash or dress myself □

Usual Activities (*e.g. work, study, housework, family or leisure activities)*

I have no problems with performing my usual activities □
I have some problems with performing my usual activities □
I am unable to perform my usual activities □

Pain/Discomfort

I have no pain or discomfort □
I have moderate pain or discomfort □
I have extreme pain or discomfort □

Anxiety/Depression

I am not anxious or depressed □
I am moderately anxious or depressed □
I am extremely anxious or depressed □

Cognition (memory, concentration, coherence, IQ)**:**

I have no problems with cognitive functioning □
I have some problems with cognitive functioning □
I have extreme problems with cognitive functioning □

Appendix E

TTO example

Health state **111111**

111111

No problems walking about
No problems washing and dressing myself
No problems with performing usual activities
No pain or discomfort
No problems with anxiety or depression
No problems with cognitive functioning

Target health state **212111**

212111

Some problems walking about
No problems washing and dressing myself
Some problems with performing usual activities
No pain or discomfort
No problems with anxiety or depression
No problems with cognitive functioning

How much time in state **111111** is equivalent to 10 years spent in the **target state?**

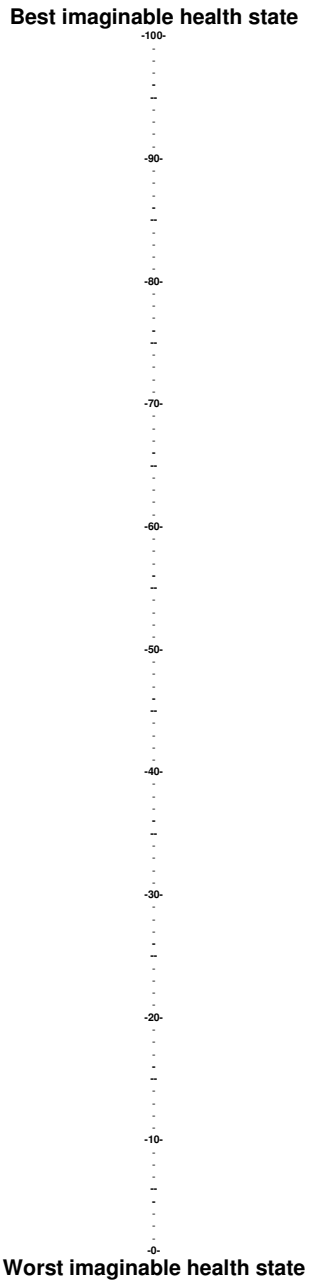
Immediate death _____
1-12 months _____
1-5 years _____
6-10 years _____
11-15 years _____
16-20 years _____
more than 20 years _____

Appendix F:

VAS example

112112

No problems walking about
No problems washing and dressing myself
Some problems with performing usual activities
No pain or discomfort
No problems with anxiety or depression
Some problems with cognitive functioning



Appendix G:

Research Institute SHARE

This thesis is published within the **Research Institute SHARE** (Science in Healthy Ageing and healthcaRE) of the University Medical Center Groningen / University of Groningen.
Further information regarding the institute and its research can be obtained from our internet site: http://www.share.umcg.nl/

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